2019

Patient Outcomes in Palliative Care - Western Australia, July - December 2018

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Abstract

The Australian palliative care sector is a world leader in using routine clinical assessment information to guide patient centred care and measure patient and family outcomes. Providers of palliative care are commended for their commitment to excellence in delivering evidence-based, patient-centred care by using the routine Palliative Care Outcomes Collaboration (PCOC) assessment framework and contributing patient data toward national outcome measurement and benchmarking. PCOC acknowledges the dedication and willingness of clinicians to improve the care of patients, their families and caregivers. The information collected is not just data - it represents the real-life outcomes of over 40,000 Australians who die an expected death every year. While the focus of this report is on the most recent information relating to July to December 2018, results over the last three years are also presented to highlight achievements and improvement in outcomes. The most recent information corresponds to 23,333 patients, having 29,931 episodes of care and 70,135 palliative care phases from 127 services who provide palliative care in hospital / hospice or in the person's home.

Keywords

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PCOC
palliative care
outcomes collaboration

Patient outcomes in Palliative Care

Western Australia

July to December 2018

April 2019

PCOC is a national palliative care project funded by the Australian Government Department of Health

What is PCOC?

The Australian Palliative Care Outcomes Collaboration (PCOC) is a national palliative care outcomes and benchmarking program. PCOC's primary objective is to systematically improve patient outcomes (including pain and symptom control).

Central to the program is a framework and protocol for routine clinical assessment and response. This works in parallel with a routine point-of-care data collection, capturing clinically meaningful information. PCOC aims to drive improvement in patient outcomes through feedback to individual services and by facilitating service-to-service benchmarking.

The items in the PCOC data collection:

- provide clinicians with an approach to systematically assess individual patient experiences
- include routine Patient Reported Outcome Measures (PROMs) relating to symptom distress
- define a common clinical language to allow palliative care providers to communicate with each other
- facilitate the routine collection of nationally consistent palliative care data for the purpose of reporting and benchmarking to drive quality improvement at service, state, territory and national levels.

The assessment framework incorporates five validated clinical assessment tools:

- Palliative Care Phase
- Palliative Care Problem Severity Score (PCPSS)
- Symptom Assessment Scale (SAS)
- Australia-modified Karnofsky Performance Status (AKPS) scale and
- Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).

If you would like more information or have any queries about this report please contact the PCOC national office at pcoc@uow.edu.au or on (02) 4221 4411

Contents

Tables

Figures

Introduction

The Australian palliative care sector is a world leader in using routine clinical assessment information to guide patient centred care and measure patient and family outcomes. Providers of palliative care are commended for their commitment to excellence in delivering evidence-based, patient-centred care by using the routine Palliative Care Outcomes Collaboration (PCOC) assessment framework and contributing patient data toward national outcome measurement and benchmarking. PCOC acknowledges the dedication and willingness of clinicians to improve the care of patients, their families and caregivers. The information collected is not just data - it represents the real-life outcomes of over 40,000 Australians who die an expected death every year.

While the focus of this report is on the most recent information relating to July to December 2018, results over the last three years are also presented to highlight achievements and improvement in outcomes. The most recent information corresponds to 23,333 patients, having 29,931 episodes of care and 70,135 palliative care phases from 127 services who provide palliative care in hospital / hospice or in the person's home.

The Western Australian figures in this report are based on information submitted by the services listed Table 1 on the following page.
A full list of the services included in the national figures can be found at www.pcoc.org.au.

Please use the following key when interpreting the tables:

-	**The item is not applicable.**
u	**The item was unavailable.**
s	**The item was suppressed due to insufficient data as there was less than 10 observations.**

Table 1 List of WA Services included in this report

Service name	Setting of care
Albany Community Hospice	Inpatient
Bethesda Hospital	Inpatient
Metropolitan Palliative Care Consultancy Service – North Team	Community
Metropolitan Palliative Care Consultancy Service – South Team	Community
Northam Palliative Care	Inpatient and community
Ramsay Health Care Peel Health Campus	Inpatient
Royal Perth Hospital	Inpatient
Royal Perth Hospital – Nurse Practitioner	Inpatient
Silver Chain Hospice Care Service – East Team	Community
Silver Chain Hospice Care Service – North Team	Community
Silver Chain Hospice Care Service – South Team	Community
St John of God – Murdoch Community Hospice	Inpatient
St John of God Bunbury Hospital	Inpatient
St John of God Geraldton Hospital	Inpatient

1 Benchmark summary for WA Services

Table 2 Summary of outcome measures by setting

Outcomes measure		Benchmark	Hospital / hospice %	Hospital / hospice BM met?	Community %	Community BM met?	Benchmark Reference No.
Timely commencement of palliative care							
Care commencing within two days of the person being ready		90%	98.1	Yes	99.9	Yes	1
Responsiveness in managing patients with urgent needs							
Patients unstable for three days or less		90%	93.3	Yes	95.4	Yes	2
Symptoms & problems in the absent to mild range at phase end							
Anticipatory care *when symptoms or problems are in the absent to mild range at phase start*	Pain (clinician reported)	90%	93.6	Yes	86.6	No	3.1
	Pain (patient reported)		92.3	Yes	85.0	No	3.3
	Fatigue (patient reported)		92.9	Yes	77.2	No	3.5
	Breathing problems (patient reported)		96.6	Yes	92.8	Yes	3.7
	Family / carer problems (clinician reported)		93.8	Yes	85.9	No	3.9
Responsive care *when symptoms or problems are in the moderate to severe range at phase start*	Pain (clinician reported)	60%	63.1	Yes	78.7	Yes	3.2
	Pain (patient reported)		56.2	No	69.5	Yes	3.4
	Fatigue (patient reported)		53.7	No	41.3	No	3.6
	Breathing problems (patient reported)		59.0	No	49.9	No	3.8
	Family / carer problems (clinician reported)		55.9	No	69.1	Yes	3.10
Casemix adjusted outcomes (change scores)			**Score**	**BM met?**	**Score**	**BM met?**	
Clinician reported problems (PCPSS)	Pain	0.0	0.17	Yes	0.06	Yes	4.1
	Other symptoms		0.30	Yes*	0.11	Yes	4.2
	Family / carer problems		0.23	Yes	0.10	Yes	4.3
	Psychological / spiritual problems		0.24	Yes	0.06	Yes	4.4
Patient reported symptom distress (SAS)	Pain	0.0	0.41	Yes	0.19	Yes	4.5
	Nausea		0.25	Yes	0.15	Yes	4.6
	Breathing problems		0.45	Yes	0.14	Yes	4.7
	Bowel problems		0.34	Yes	0.24	Yes	4.8

* The item completion for this benchmark was less than 80%. This result may not be reflective of your service. See Appendix A for more details.

2 Patient outcomes in more detail

2.1 Timely commencement of palliative care

Time from date ready for care to episode start reports responsiveness of palliative care services to patient needs. This benchmark was set following feedback and subsequent consultation with PCOC participants. Service providers acknowledge that, whilst there is wide variation in the delivery of palliative care across the country, access to palliative care should be measured based on patient need rather than service availability. As a result, services operating five days a week (Monday to Friday) are not distinguished from services operating seven days a week (All services are being benchmarked together).

Benchmark 1: This measure relates to the time taken for an episode to commence following the date the patient is available and ready to receive palliative care. To meet the benchmark for this measure, at least 90% of patients must have their episode commence on the day of, or the day following, date ready for care.

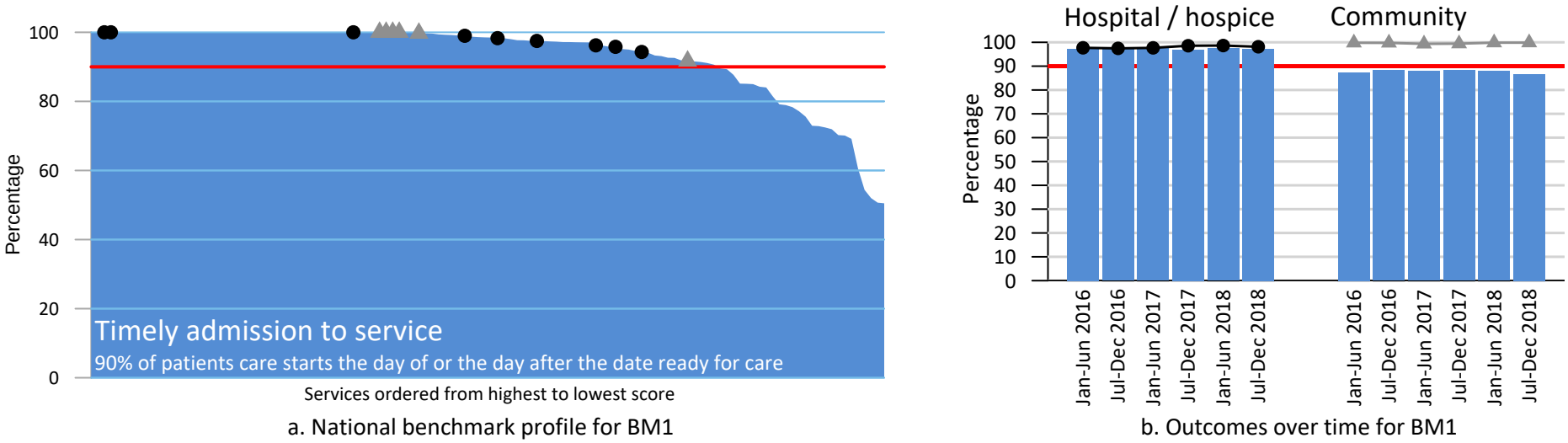
Table 3 Time from date ready for care to episode start by setting

Time (in days)	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N	%	N	%	N	%	N	%
Same day	1,263	90.7	12,822	92.5	2,861	99.8	10,483	82.0
Following day	104	7.5	643	4.6	2	0.1	597	4.7
2-7	25	1.8	357	2.6	2	0.1	1,198	9.4
8-14	0	0	23	0.2	0	0	296	2.3
15 +	1	0.1	10	0.1	2	0.1	211	1.7
Average	1.1	-	1.1	-	1.0	-	2.1	-
Median	1	-	1	-	1	-	1	-

Note: Only episodes that started in this reporting period have been included in the table. Episodes where date ready for care was not recorded are excluded from the table. In addition, all records where time from date ready for care to episode start was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

Interpretation hint:
Outcome measure 1 only includes episodes that have commenced in the reporting period. As a result, the number of episodes included in the calculation of this benchmark may not match the number of episodes in Appendix A. For more information on data scoping methods, see Appendix C.

Figure 1 **Time from date ready for care to episode start, Western Australian services compared to all services (BM1)**



Note: Only services with 10 or more valid assessments are included in the above graphs.

2.2 Responsiveness in managing patients with urgent needs

The unstable phase type, by nature of its definition, alerts clinical staff to the need for urgent changes to the patient's plan of care or that emergency intervention is required. Those patients assessed to be in the unstable phase require intense review for a short period of time.

An unstable phase is triggered if:

- a patient experiences a new, unanticipated problem, and / or
- a patient experiences a rapid increase in the severity of an existing problem, and / or
- a patient's family / carers experience a sudden change in circumstances that adversely impacts the patient's care.

The patient moves out of the unstable phase in one of two ways:

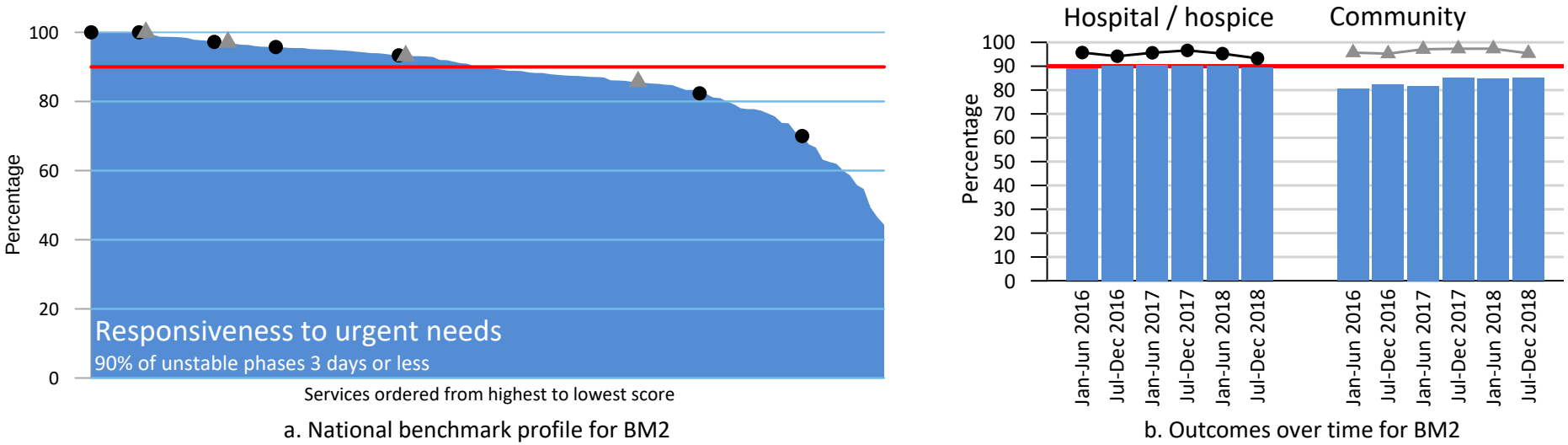
- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom / crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient's care. In this situation, the patient will move to either the stable or deteriorating phase.
- The patient is likely to die within a matter of days. In this situation, the patient will be moved into the terminal phase.

Benchmark 2: This benchmark relates to the time that a patient spends in the unstable phase. To meet this benchmark, at least 90% of unstable phases must last for three days or less.

Table 4 Time in unstable phase by setting

Time in unstable phase	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N	%	N	%	N	%	N	%
Same day	44	11.4	362	5.3	158	40.3	1,415	31.3
1 day	217	56.1	3,515	51.9	184	46.9	1,648	36.4
2 days	67	17.3	1,509	22.3	21	5.4	524	11.6
3 days	33	8.5	666	9.8	11	2.8	259	5.7
4 – 5 days	16	4.1	470	6.9	7	1.8	209	4.6
6 – 7 days	4	1.0	139	2.1	5	1.3	146	3.2
8 – 14 days	4	1.0	91	1.3	6	1.5	156	3.4
More than 14 days	2	0.5	25	0.4	0	0.0	165	3.6
Total	387	100.0	6,777	100.0	392	100.0	4,522	100.0

Figure 2 **Time in unstable phase, Western Australian services compared to all services (BM2)**



Note: Only services with 10 or more valid assessments are included in the above graphs.

2.3 Symptoms & problems in the absent to mild range at phase end

The outcome measures presented in this section focus on five symptom and problem areas:

1. Pain - clinician reported severity
2. Pain - patient reported distress
3. Fatigue - patient reported distress
4. Breathing problems - patient reported distress
5. Family / carer problems - clinician reported severity

A positive patient outcome is achieved if the patient, or family/carer, has an absent to mild symptom / problem at the end of a palliative care phase. However, the type of care delivered and the corresponding benchmarks achievement depends on the patient's (or family/carer) level of symptom or problem at start of the phase; scores in the absent to mild range trigger monitoring and review of care plans (anticipatory care), whilst scores in the moderate to severe range trigger interventions and actions to respond to needs (responsive care).

Anticipatory care

The anticipatory care outcome measures and benchmarks relate to patients who have absent or mild symptom / problem at the start of a phase of palliative care. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild symptom / problem. Table 5 summarises the number of phases starting with absent to mild symptom / problem, and the percentage of those ending in the absent to mild range.

Table 5 Achieving absent to mild symptoms/problems at phase end, when absent to mild at beginning

Symptom / problem[a]	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N[b]	%	N[b]	%	N[b]	%	N[b]	%
Pain (clinician reported)	1,845	93.6	19,193	91.8	6,990	86.6	21,147	85.2
Pain (patient reported)	1,622	92.3	16,495	90.8	6,738	85.0	20,932	84.2
Fatigue (patient reported)	1,572	92.9	15,684	90.8	5,077	77.2	16,437	80.4
Breathing problems (patient reported)	1,857	96.6	18,817	95.6	7,154	92.8	21,325	92.5
Family / carer problems (clinician reported)	1,458	93.8	20,112	93.2	6,474	85.9	19,635	84.4

a. Phase records must have valid start and end scores for the PCPSS and / or SAS clinical assessment tools to enable outcomes to be measured.

b. N represents the total number of phases starting with **absent to mild** symptom / problem.

Responsive care

The responsive care outcome measure and benchmarks relate to patients, or family/carer, who have a moderate or severe symptom / problem at the start of their phase of palliative care. Achieving an absent / mild symptom or problem outcome at phase end has been identified as more clinically challenging, so to meet this benchmark, 60% of these phases must end with the patient experiencing absent or mild symptom / problem.

Table 6 summarises the number of phases starting with moderate to severe symptom / problem and of those, the percentage ending in the absent to mild range.

Table 6 Achieving absent to mild symptoms/problems at phase end, when moderate to severe at beginning

Symptom / problem[a]	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N[b]	%	N[b]	%	N[b]	%	N[b]	%
Pain (clinician reported)	358	63.1	4,993	61.7	1,198	78.7	4,621	59.0
Pain (patient reported)	575	56.2	5,690	58.1	1,438	69.5	5,583	53.3
Fatigue (patient reported)	618	53.7	6,473	53.2	3,086	41.3	8,740	37.0
Breathing problems (patient reported)	339	59.0	3,337	52.6	1,014	49.9	3,470	39.6
Family / carer problems (clinician reported)	279	55.9	3,253	56.3	1,130	69.1	4,520	48.6

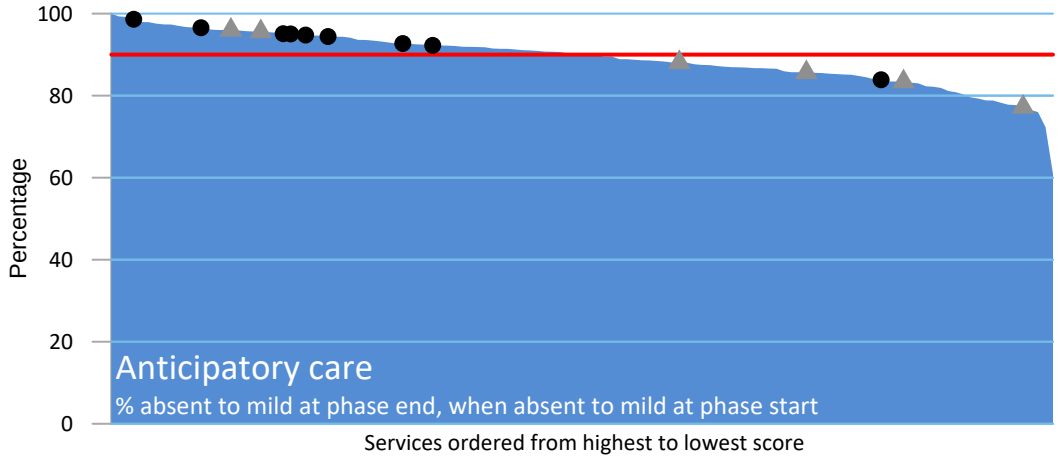
a. Phase records must have valid start and end scores for the PCPSS and / or SAS clinical assessment tools to enable outcomes to be measured.

b. N represents the total number of phases starting with the symptom or problem rated **moderate to severe**.

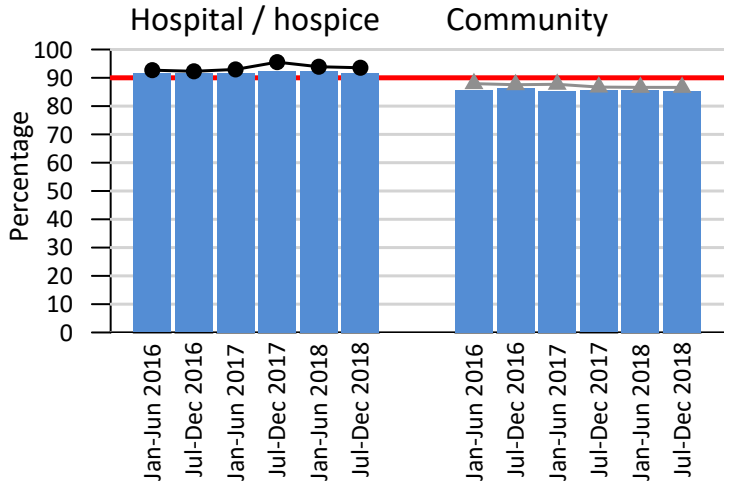
On the following pages, the results for the anticipatory and responsive care benchmarks are presented together for each of the five symptom and problem domains. The graphs included compare the outcomes achieved by your service to those of other individual services nationally, as well as showing any changes in outcomes over time.

Pain (clinician reported problem severity)

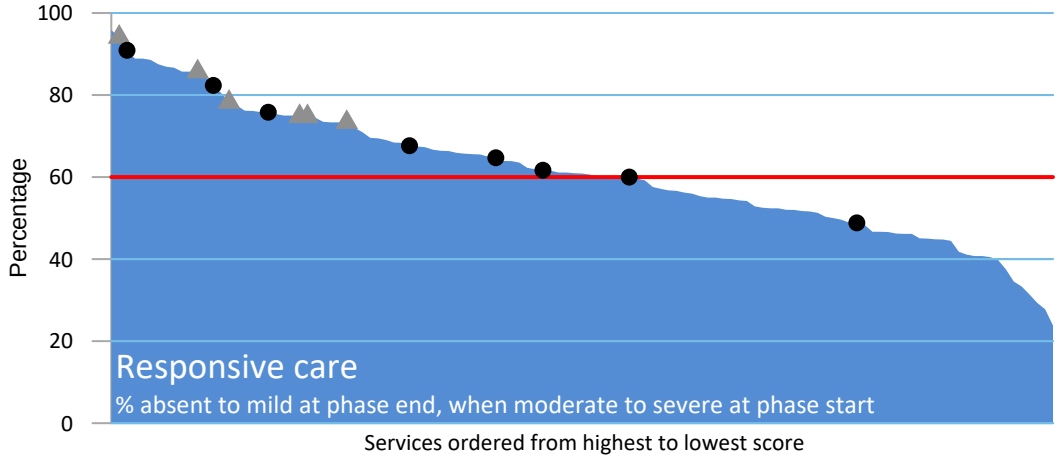
Figure 3 **Pain, patients with absent to mild problem at phase end**



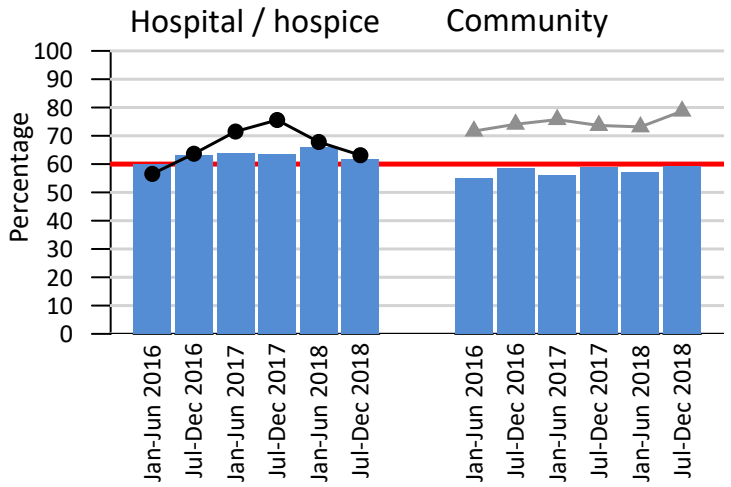
a. National service profile for BM3.1



b. Outcomes over time (BM3.1)



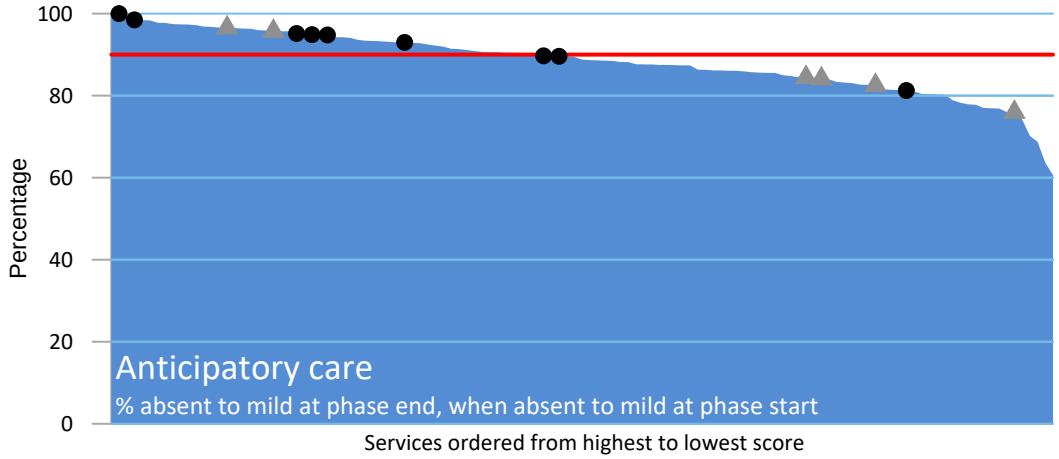
c. National service profile for BM3.2



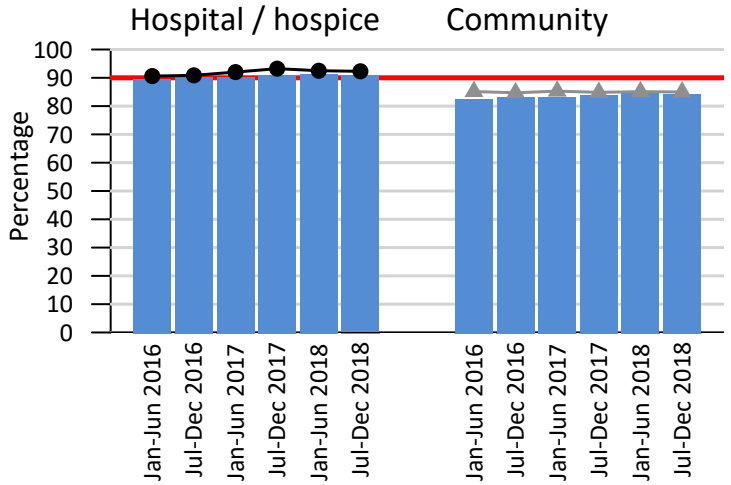
d. Outcomes over time (BM3.2)

Note: Only services with 10 or more valid assessments are included in the above graphs.

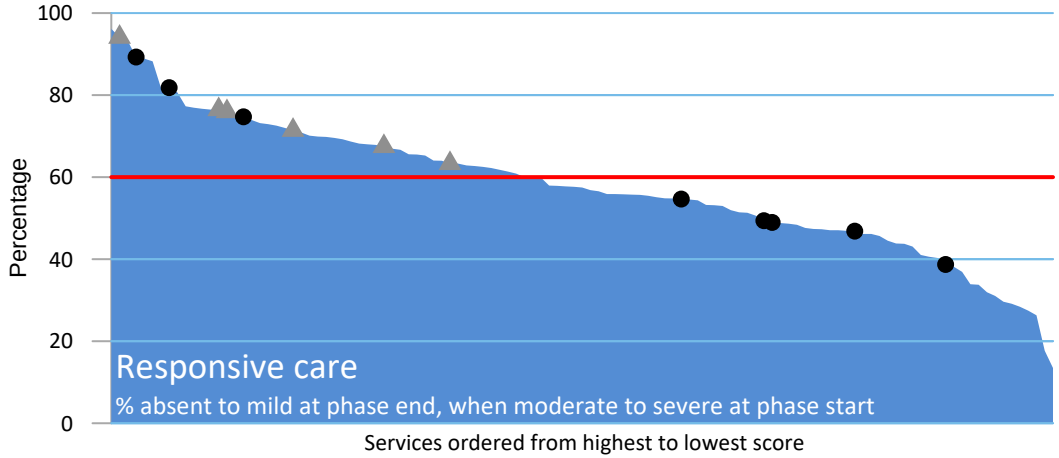
Figure 4 **Pain, patients experiencing absent to mild distress at phase end**



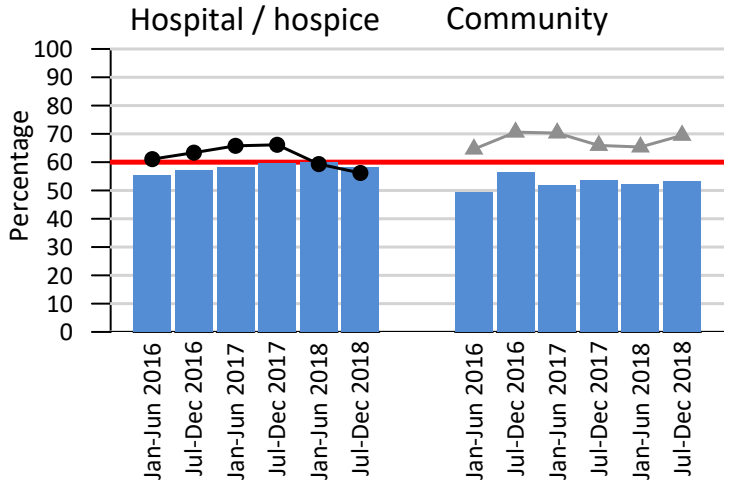
a. National benchmark profile for BM3.3



b. Outcomes over time BM3.3



c. National benchmark profile for BM3.4

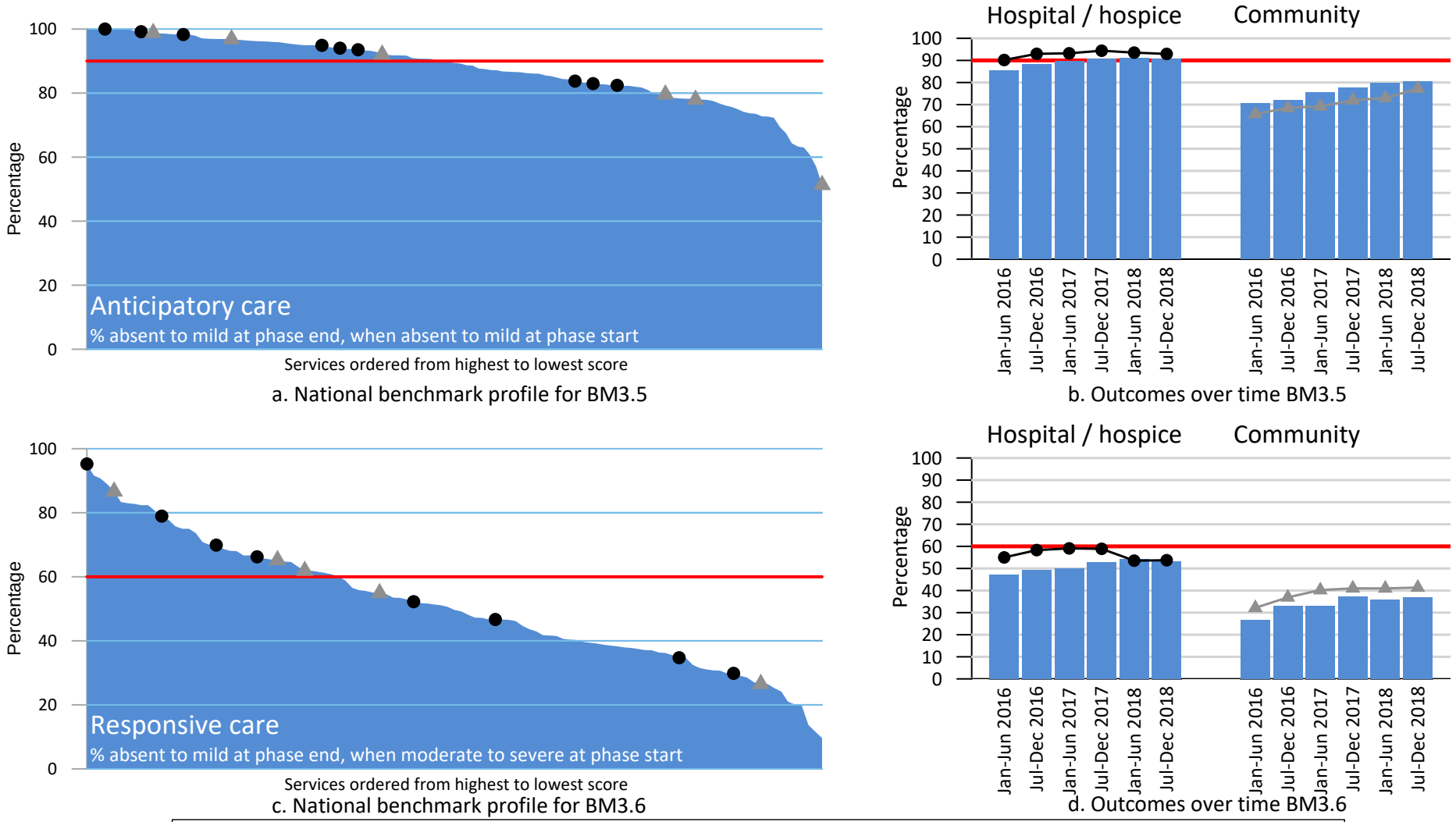


d. Outcomes over time BM3.4

Note: Only services with 10 or more valid assessments are included in the above graphs.

Fatigue (patient reported distress)

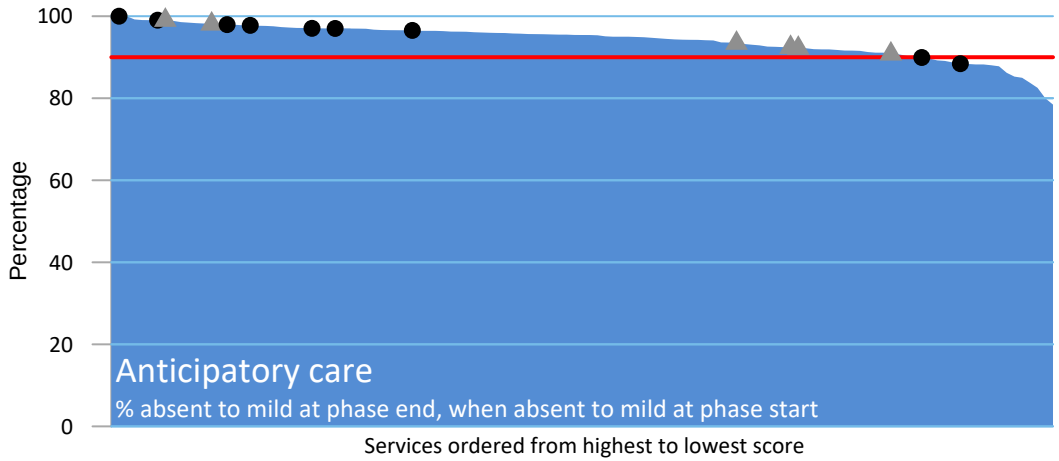
Figure 5 **Fatigue, patients experiencing absent to mild distress at phase end**



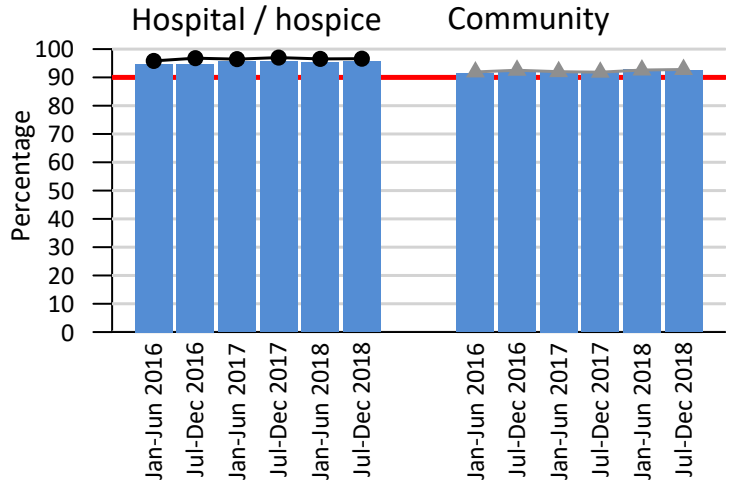
Note: Only services with 10 or more valid assessments are included in the above graphs.

Breathing problems (patient reported distress)

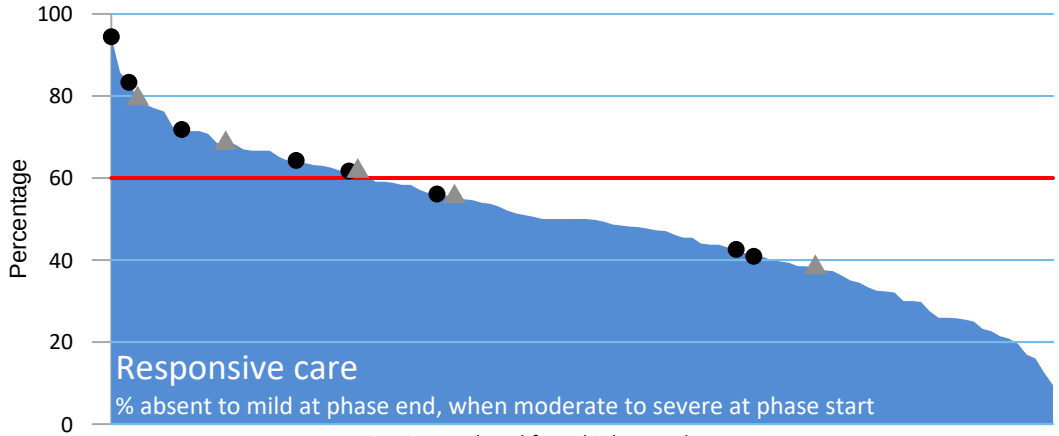
Figure 6 **Breathing problems, patients experiencing absent to mild distress at phase end**



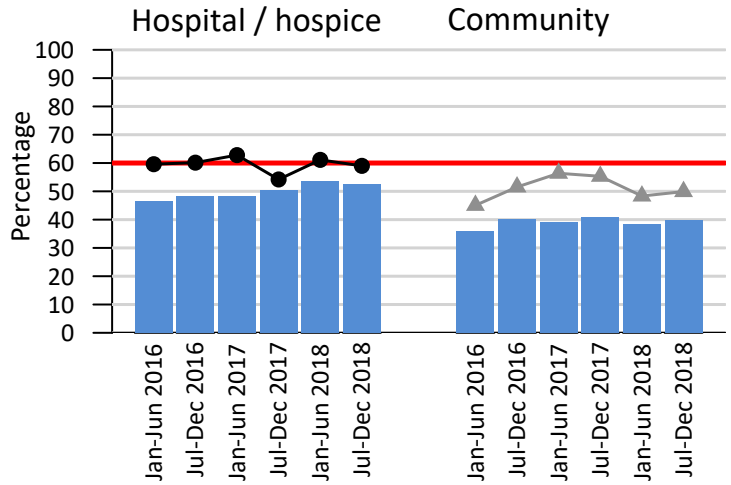
a. National benchmark profile for BM3.7



b. Outcomes over time BM3.7



c. National benchmark profile for BM3.8

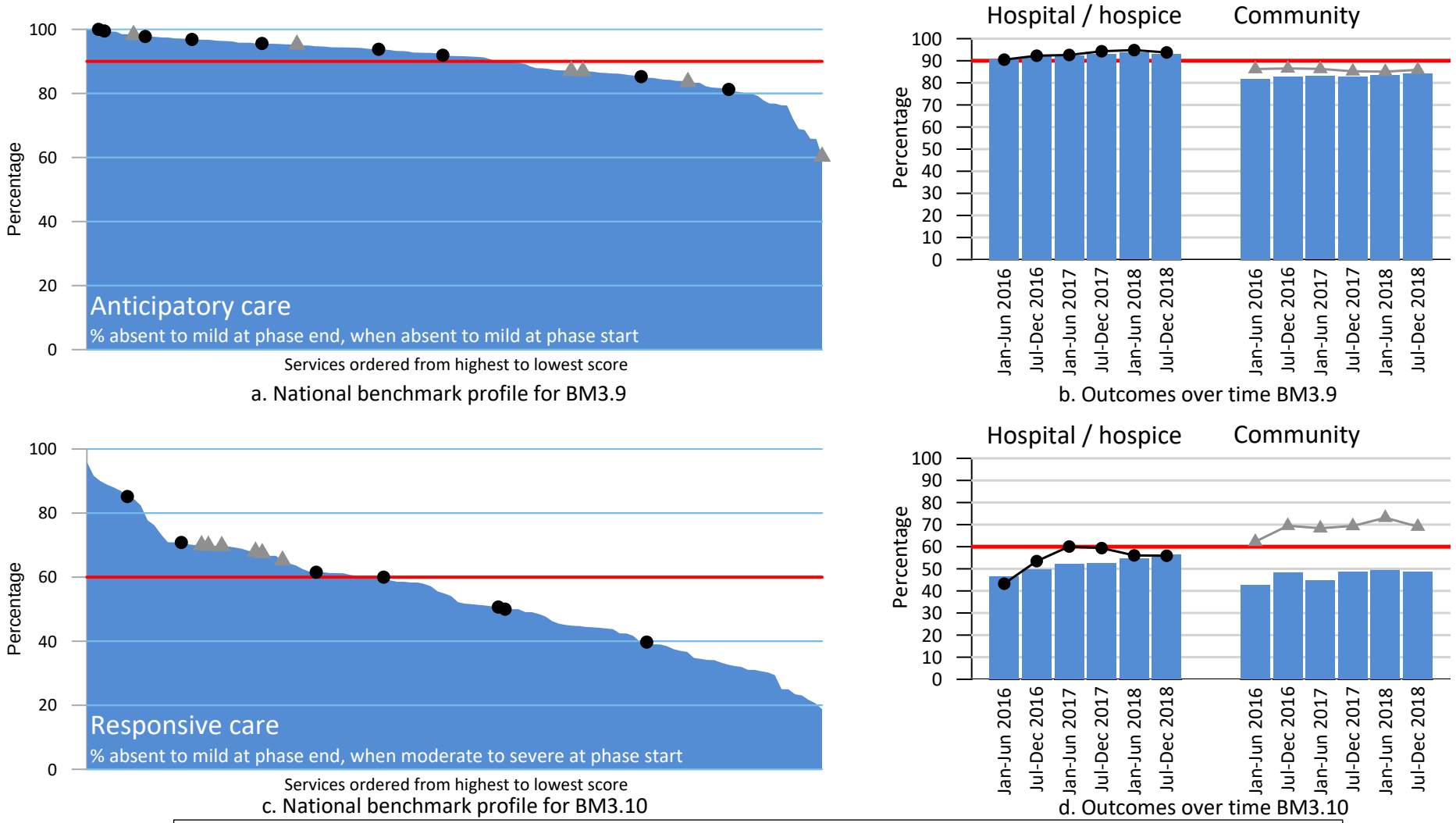


d. Outcomes over time BM3.8

Note: Only services with 10 or more valid assessments are included in the above graphs.

Family / carer problems (clinician reported problem severity)

Figure 7 Family / carer problems, absent to mild at phase end



Note: Only services with 10 or more valid assessments are included in the above graphs.

2.4 Casemix adjusted outcomes

Outcome measure 4 includes a suite of eight casemix adjusted scores used to compare the change in symptoms for similar patients. Patients in the same phase who started with the same level of symptom have their change in symptom compared to the reference period (January to June 2014).

Table 7 Casemix adjusted outcomes – hospital / hospice setting

Clinical tool	Symptom / problem	WA Services				All services			
		Casemix adjusted score	Phases included (N)	Phases at or above baseline (N)	Phases at or above baseline (%)	Casemix adjusted score	Phases included (N)	Phases at or above baseline (N)	Phases at or above baseline (%)
PCPSS *Clinician reported severity*	**Pain**	0.17	2,203	1,510	68.5	0.09	24,186	14,946	61.8
	Other symptoms	0.30	1,766	1,383	78.3	0.24	23,703	18,061	76.2
	Family / carer	0.23	1,737	1,314	75.6	0.19	23,365	16,913	72.4
	Psychological / spiritual	0.24	2,191	1,541	70.3	0.20	24,145	15,655	64.8
SAS *Patient reported distress*	**Pain**	0.41	2,197	1,556	70.8	0.34	22,185	15,241	68.7
	Nausea	0.25	2,196	1,966	89.5	0.21	22,104	19,518	88.3
	Breathing problems	0.45	2,196	1,811	82.5	0.33	22,154	17,730	80.0
	Bowel problems	0.34	2,193	1,837	83.8	0.31	22,114	17,853	80.7

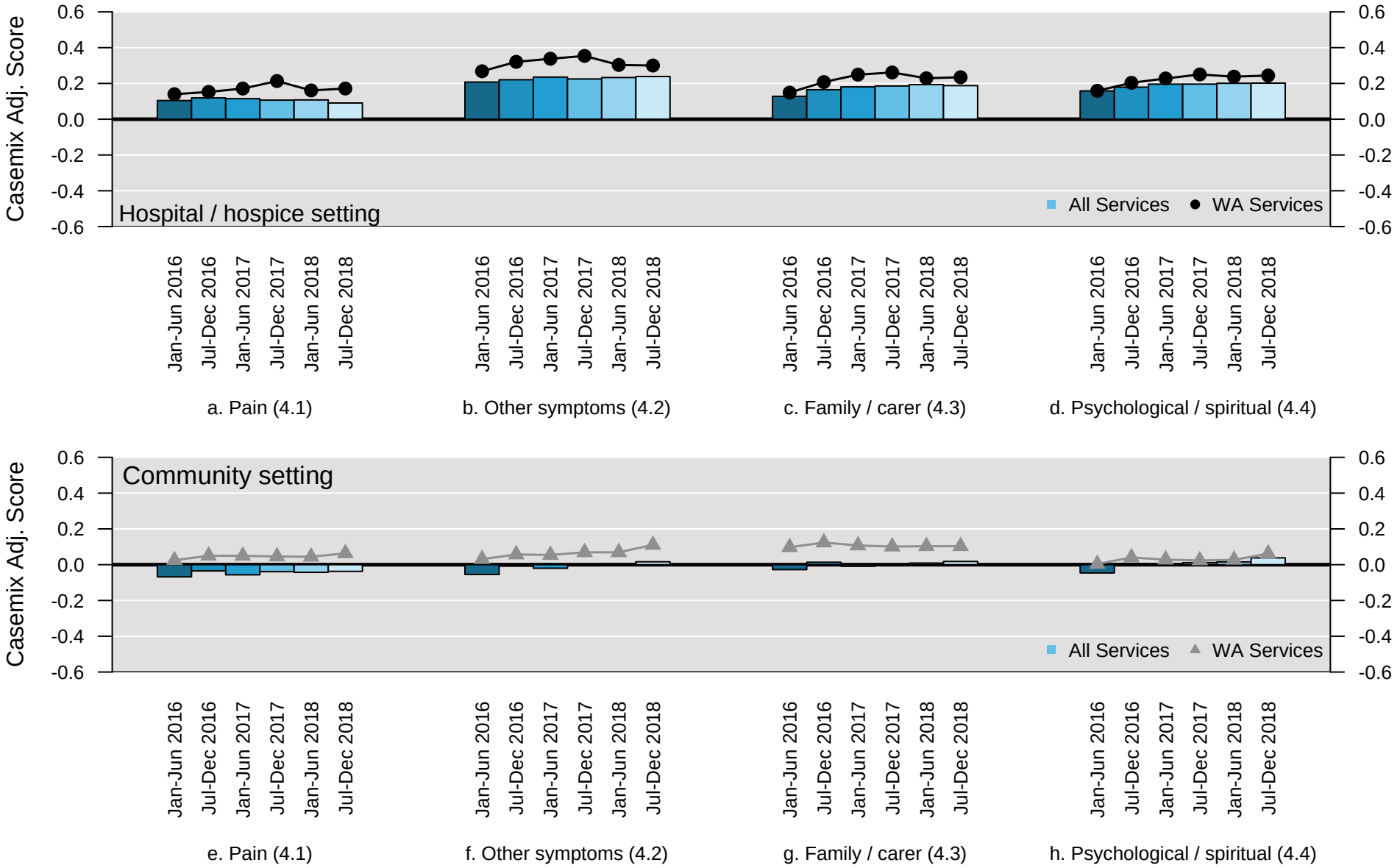
The Casemix adjusted scores are calculated relative to a baseline reference period. A Casemix adjusted score:

- **greater than 0** means that on average your patient's outcomes were **better than for similar patients** in the reference period
- **less than 0** means that on average, your patients' outcomes were **worse than to similar patients** in the reference period
- **equal to 0** means that on average, your patients' outcomes were **about the same as similar patients** in the reference period

Table 8 Casemix adjusted outcomes – community setting

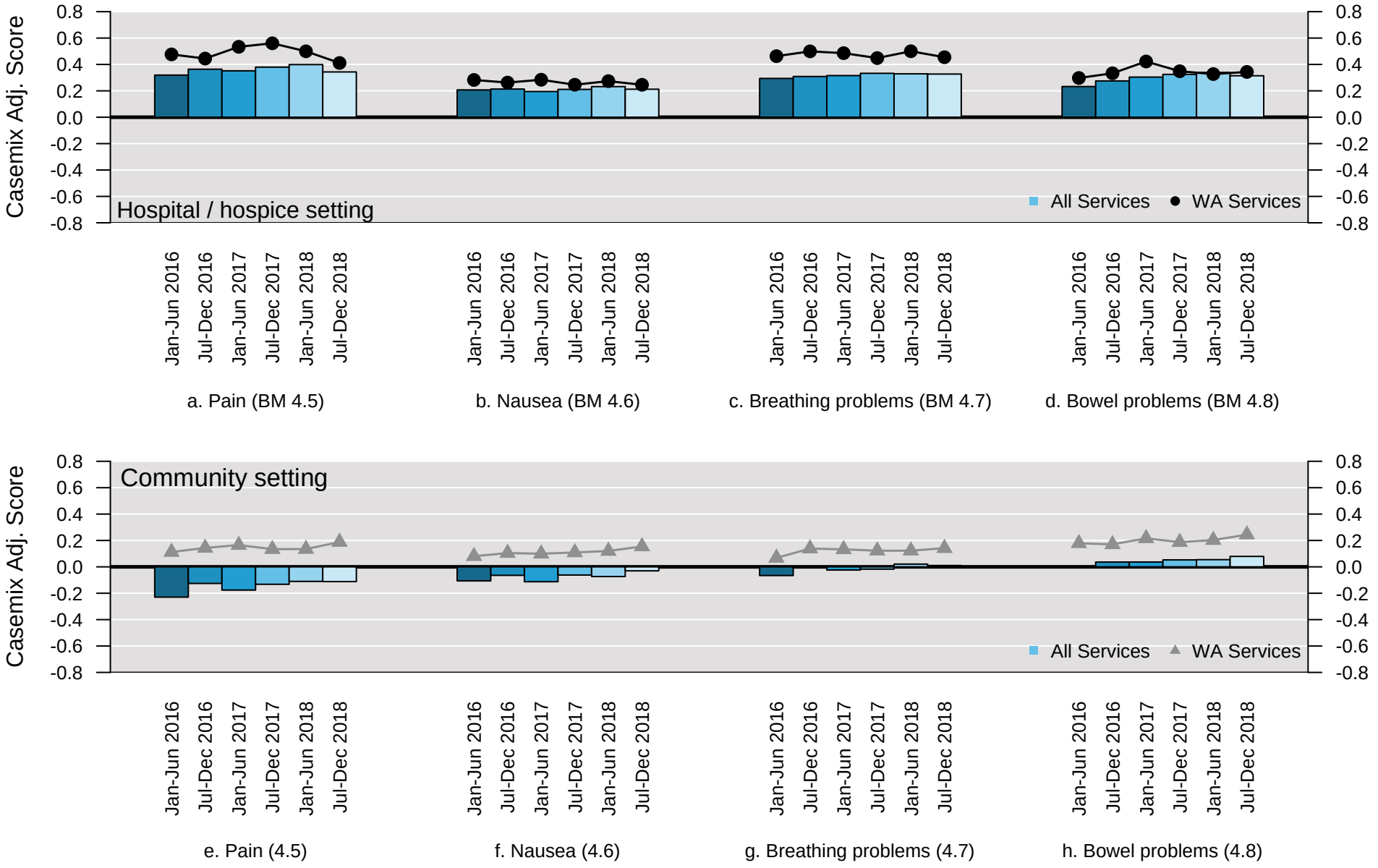
Clinical tool	Symptom /problem	WA Services				All services			
		Casemix adjusted score	Phases included (N)	Phases at or above baseline (N)	Phases at or above baseline (%)	Casemix adjusted score	Phases included (N)	Phases at or above baseline (N)	Phases at or above baseline (%)
PCPSS	**Pain**	0.06	8,188	5,041	61.6	-0.04	25,768	14,274	55.4
Clinician	**Other symptoms**	0.11	8,189	5,683	69.4	0.02	25,089	16,292	64.9
reported	**Family / carer**	0.10	7,604	5,359	70.5	0.02	24,155	15,749	65.2
severity	**Psychological / spiritual**	0.06	8,201	4,535	55.3	0.04	25,441	13,769	54.1
SAS	**Pain**	0.19	8,176	5,413	66.2	-0.11	26,515	15,674	59.1
Patient	**Nausea**	0.15	8,158	7,229	88.6	-0.03	25,013	20,258	81.0
reported	**Breathing problems**	0.14	8,168	5,952	72.9	0.01	24,795	17,084	68.9
distress	**Bowel problems**	0.24	8,153	6,634	81.4	0.08	24,553	18,379	74.9

Figure 8 **Trends in casemix adjusted outcomes - Palliative Care Problem Severity Score (PCPSS)**



Note: Only services with 10 or more valid assessments are included in the above graphs.

Figure 9 **Trends in casemix adjusted outcomes - Symptom Assessment Scale (SAS)**



Note: Only services with 10 or more valid assessments are included in the above graphs.

3 Patient characteristics

PCOC defines a patient as a person for whom a palliative care service accepts responsibility for assessment and / or treatment as evidenced by the existence of a medical record. Family and carers are included in this definition if interventions relating to them are recorded in the patient medical record.

Table 9 shows the Indigenous status for the patients in Western Australian services and nationally.

Table 9 Indigenous status

Indigenous status	WA Services		All services	
	N	%	N	%
Aboriginal but not Torres Strait Islander origin	52	1.4	311	1.3
Torres Strait Islander but not Aboriginal origin	1	0.0	20	0.1
Both Aboriginal and Torres Strait Islander origin	6	0.2	30	0.1
Neither Aboriginal nor Torres Strait Islander origin	3,634	95.3	22,161	95.0
Not stated / inadequately described	120	3.1	811	3.5
Total	3,813	100.0	23,333	100.0

Table 10 shows the breakdown of deaths for the patients in Western Australian services and nationally for the reporting period. All inpatient deaths are reported in the hospital / hospice category while the community deaths are reported in the private residence and residential aged care facility categories.

Table 10 Place of death

Place of death	WA Services		All services	
	N	%	N	%
Private residence	638	37.4	2,346	20.9
Residential aged care facility	321	18.8	892	8.0
Hospital / hospice	748	43.8	7,938	70.8
Not stated / inadequately described	0	0.0	38	0.3
Total	1,707	100.0	11,214	100.0

Table 11 Country of birth

Country of birth	WA Services		All services	
	N	%	N	%
Australia	2,145	56.3	14,141	60.6
England	559	14.7	1,666	7.1
New Zealand	78	2.0	459	2.0
China	11	0.3	248	1.1
India	51	1.3	203	0.9
Italy	149	3.9	927	4.0
Vietnam	28	0.7	187	0.8
Philippines	11	0.3	117	0.5
South Africa	33	0.9	123	0.5
Scotland	87	2.3	282	1.2
Malaysia	30	0.8	97	0.4
Germany	30	0.8	253	1.1
Greece	20	0.5	518	2.2
Sri Lanka	9	0.2	85	0.4
United States of America	12	0.3	56	0.2
All other countries	460	12.1	3,257	14.0
Not stated	100	2.6	714	3.1
Total	3,813	100.0	23,333	100.0

Table 12 Preferred language

Language	WA Services		All services	
	N	%	N	%
English	3,574	93.7	20,626	88.4
Chinese[(a)]	18	0.5	284	1.2
Hindi[(b)]	2	0.1	44	0.2
Arabic[(c)]	5	0.1	220	0.9
Italian	52	1.4	436	1.9
Vietnamese[(d)]	11	0.3	123	0.5
Greek	6	0.2	345	1.5
Filipino / Indonesian[(e)]	9	0.2	42	0.2
Macedonian / Croatian[(f)]	17	0.4	198	0.8
Spanish[(g)]	7	0.2	83	0.4
Tamil / Malayalam[(h)]	0	0.0	7	0.0
German[(i)]	4	0.1	20	0.1
Korean	1	0.0	30	0.1
Samoan / Tongan[(j)]	2	0.1	27	0.1
African languages	1	0.0	13	0.1
All other languages	49	1.3	412	1.8
Not stated	55	1.4	423	1.8
Total	3,813	100.0	23,333	100.0

Also includes

(a) Cantonese, Hakka, Mandarin, Wu and Min Nan
(b) Bengali, Gujarati, Konkani, Marathi, Nepali, Punjabi, Sindhi, Sinhalese, Urdu, Assamese, Dhivehi, Kashmiri, Oriya, and Fijian Hindustani
(c) Hebrew, Assyrian Neo-Aramaic, Chaldean Neo-Aramaic, and Mandaean (Mandaic)
(d) Khmer and Mon
(e) Bisaya, Cebuano, Ilokano, Malay, Tetum, Timorese, Tagalog, Acehnese, Balinese, Bikol, Iban, Ilonggo, Javanese, and Pampangan
(f) Bosnian, Bulgarian, Serbian, and Slovene
(g) Catalan and Portuguese
(h) Kannada, Telugu, and Tulu
(i) Letzeburgish and Yiddish
(j) Fijian, Gilbertese, Maori, Nauruan, Niue, Rotuman, Tokelauan, Tuvaluan, and Yapese

The tables on this page show the country of birth and the preferred language respectively for the patients in Western Australian services and nationally. To allow for comparison with the broader Australian community the list of country of birth in Table 11 is in descending order of the most frequent country of birth according to the 2011 Census (e.g. India was the fifth most common country of birth in the 2011 Census). The same approach has been taken with Table 12 (e.g. Italian was the fifth most frequently spoken language in the 2011 census). All other countries and languages have been grouped together to form the categories ‘All other countries’ and ‘All other languages’ respectively.

Table 13 and Table 14 present a breakdown of malignant and non-malignant diagnosis for the patients in Western Australian services and at the national level. Diagnosis is the principal life limiting illness responsible for the patient requiring palliative care.

Diagnosis was not stated for 3 (0.1%) patients in Western Australian services and was not stated for 170 (0.7%) patients nationally.

Table 13 Principal reason for palliative care - malignant diagnoses

Diagnosis	WA Services			All services		
	N	% of malignant diagnoses	% of all diagnoses	N	% of malignant diagnoses	% of all diagnoses
Bone and soft tissue	23	1.0	0.6	237	1.4	1.0
Breast	164	6.9	4.3	1,280	7.5	5.5
CNS	65	2.7	1.7	349	2.0	1.5
Colorectal	245	10.3	6.4	1,816	10.6	7.8
Other GIT	234	9.8	6.1	1,571	9.2	6.7
Haematological	191	8.0	5.0	1,104	6.5	4.7
Head and neck	75	3.1	2.0	864	5.1	3.7
Lung	545	22.8	14.3	3,677	21.5	15.8
Pancreas	188	7.9	4.9	1,287	7.5	5.5
Prostate	187	7.8	4.9	1,238	7.2	5.3
Other urological	107	4.5	2.8	765	4.5	3.3
Gynaecological	119	5.0	3.1	845	4.9	3.6
Skin	97	4.1	2.5	609	3.6	2.6
Unknown primary	59	2.5	1.5	475	2.8	2.0
Other primary malignancy	75	3.1	2.0	731	4.3	3.1
Malignant – nfd	15	0.6	0.4	234	1.4	1.0
All malignant diagnoses	2,389	100.0	62.7	17,082	100.0	73.2

Table 14 Principal reason for palliative care - non-malignant diagnoses

Diagnosis	WA Services			All services		
	N	% non-malignant	% all diagnoses	N	% non-malignant	% all diagnoses
Cardiovascular disease	211	14.8	5.5	1,022	16.8	4.4
HIV / AIDS	1	0.1	0.0	4	0.1	0.0
End stage kidney disease	94	6.6	2.5	532	8.7	2.3
Stroke	74	5.2	1.9	328	5.4	1.4
Motor neurone disease	55	3.9	1.4	284	4.7	1.2
Alzheimer's dementia	111	7.8	2.9	234	3.8	1.0
Other dementia	207	14.6	5.4	448	7.4	1.9
Other neurological disease	85	6.0	2.2	323	5.3	1.4
Respiratory failure	192	13.5	5.0	1,063	17.5	4.6
End stage liver disease	40	2.8	1.0	246	4.0	1.1
Diabetes & its complications	7	0.5	0.2	34	0.6	0.1
Sepsis	74	5.2	1.9	284	4.7	1.2
Multiple organ failure	21	1.5	0.6	146	2.4	0.6
Other non-malignancy	238	16.7	6.2	932	15.3	4.0
Non-malignant – nfd	11	0.8	0.3	201	3.3	0.9
All non-malignant	1,421	100.0	37.3	6,081	100.0	26.1

4 Episodes of palliative care

An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting – for the purposes of this report, either as a hospital / hospice or community patient.

An episode of palliative care starts on the date when the comprehensive palliative care assessment is undertaken and documented using the five clinical assessment tools.

An episode of palliative care ends when:

- the patient is formally separated from the current setting of care (e.g. from community to hospital / hospice) or
- the patient dies or
- the principal clinical intent of the care changes and the patient is no longer receiving palliative care.

Table 15 presents the number and percentage of episodes by age group and sex for the patients seen by Western Australian services and at the national level. Age has been calculated as at the beginning of each episode.

Table 15 Patient's age by sex

Age group	WA Services				All services			
	Male		Female		Male		Female	
	N	%	N	%	N	%	N	%
< 15	7	0.3	4	0.2	24	0.2	24	0.2
15 - 24	6	0.2	6	0.3	48	0.3	17	0.1
25 - 34	19	0.8	7	0.3	137	0.9	120	0.9
35 - 44	20	0.8	58	2.6	205	1.3	446	3.2
45 - 54	110	4.4	146	6.5	867	5.5	993	7.1
55 - 64	349	14.0	320	14.2	2,322	14.6	2,150	15.3
65 - 74	602	24.2	476	21.1	4,143	26.1	3,281	23.4
75 - 84	787	31.7	509	22.6	4,804	30.2	3,433	24.5
85 +	585	23.5	728	32.3	3,291	20.7	3,529	25.1
Unknown	0	0.0	0	0.0	47	0.0	45	0.0
Total	2,485	100.0	2,254	100.0	15,888	100.0	14,038	100.0

Note: Records where sex was not stated or inadequately described are excluded from the table.

Referral source refers to the facility or organisation from which the patient was referred for each episode of care. Table 16 presents referral source by setting.

Table 16 Source of referral

Referral source	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N	%	N	%	N	%	N	%
Public hospital	820	57.5	9,002	61.3	1,296	39.1	8,219	53.9
Private hospital	69	4.8	1,368	9.3	386	11.7	1,698	11.1
Outpatient clinic	4	0.3	96	0.7	0	0.0	127	0.8
General medical practitioner	37	2.6	330	2.2	962	29.0	2,260	14.8
Specialist medical practitioner	196	13.7	509	3.5	0	0.0	857	5.6
Community-based palliative care agency	263	18.4	2,860	19.5	6	0.2	216	1.4
Community-based service	2	0.1	35	0.2	18	0.5	177	1.2
Residential aged care facility	5	0.4	69	0.5	600	18.1	785	5.1
Self, carer(s), family or friends	11	0.8	115	0.8	7	0.2	471	3.1
Other	20	1.4	156	1.1	37	1.1	382	2.5
Not stated / inadequately described	0	0.0	139	0.9	0	0.0	60	0.4
Total	1,427	100.0	14,679	100.0	3,312	100.0	15,252	100.0

Table 17 gives a summary of the length of episode for patients in Western Australian services and nationally. Table 18 details the length of episode by setting. The length of episode is calculated as the number of days between the episode start date and the episode end date. Bereavement phases are excluded from the calculation and episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

Table 17 Length of episode (in days) summary by setting

Length of episode	Hospital / hospice		Community	
	WA Services	All services	WA Services	All services
Average length of episode	8.6	10.1	30.2	37.4
Median length of episode	5.0	6.0	19.0	25.0

Note: Records where length of episode was greater than 180 days were considered to be atypical and are excluded from the average calculations. Only episodes ending during the reporting period are included.

Table 18 Length of episode by setting

Length of Episode (days)	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N	%	N	%	N	%	N	%
Same day	91	6.5	1,022	7.1	62	2.2	352	2.7
1-2	364	25.9	2,933	20.2	181	6.3	831	6.3
3-4	211	15.0	2,163	14.9	200	7.0	813	6.1
5-7	260	18.5	2,469	17.0	284	10.0	1,094	8.3
8-14	247	17.6	2,866	19.8	488	17.1	1,792	13.5
15-21	111	7.9	1,291	8.9	342	12.0	1,236	9.3
22-30	48	3.4	832	5.7	333	11.7	1,215	9.2
31-60	62	4.4	741	5.1	482	16.9	2,235	16.9
61-90	7	0.5	124	0.9	182	6.4	1,117	8.4
90 +	4	0.3	48	0.3	300	10.5	2,570	19.4
Total	1,405	100.0	14,489	100.0	2,854	100.0	13,255	100.0

Note: Only episodes that end during the reporting period are included.

Table 19 How hospital / hospice episodes start

Episode start mode	WA Services		All services	
	N	%	N	%
Admitted from community[1]	897	62.9	8,754	59.6
Admitted from another hospital	437	30.6	3,199	21.8
Admitted from acute care in another ward	72	5.0	2,316	15.8
Change from acute care to palliative care – same ward	9	0.6	236	1.6
Other[2]	11	0.8	96	0.7
Not stated / inadequately described	1	0.1	78	0.5
Total	1,427	100.0	14,679	100.0

[1] includes: admitted from usual accommodation, admitted from other than usual accommodation.

[2] includes: change of sub-acute/non-acute care type and other categories.

Table 20 How hospital / hospice episodes end

Episode end mode	WA Services		All services	
	N	%	N	%
Discharged to community[1]	592	42.1	4,887	33.7
Discharged to another hospital	31	2.2	735	5.1
Death	748	53.2	7,938	54.7
Change from palliative care to acute care[2]	1	0.1	176	1.2
Change in sub-acute care type	0	0.0	174	1.2
End of consultative episode – inpatient episode ongoing	19	1.4	498	3.4
Other	14	1.0	68	0.5
Not stated / inadequately described	0	0.0	26	0.2
Total	1,405	100.0	14,502	100.0

Note: Only episodes ending during the reporting period are included.

[1] includes: discharged to usual accommodation, discharged to other than usual accommodation.

[2] includes: change from palliative care to acute care – different ward, change from palliative care to acute care – same ward.

Table 21 How community episodes start

Episode start mode	WA Services		All services	
	N	%	N	%
Admitted from inpatient palliative care	1,925	58.1	5,780	37.9
Other[1]	1,387	41.9	9,384	61.5
Not stated / inadequately described	0	0.0	88	0.6
Total	3,312	100.0	15,252	100.0

[1]includes: patient was not transferred from being an overnight patient.

Table 22 How community episodes end

Episode end mode	WA Services		All services	
	N	%	N	%
Admitted for inpatient palliative care	55	1.9	4,024	30.3
Admitted for inpatient acute care	1,206	42.3	4,045	30.5
Admitted to another palliative care service	19	0.7	92	0.7
Admitted to primary health care	372	13.0	583	4.4
Discharged / case closure	243	8.5	1,020	7.7
Death	959	33.6	3,276	24.7
Other	0	0.0	184	1.4
Not stated / inadequately described	0	0.0	41	0.3
Total	2,854	100.0	13,265	100.0

Note: Only episodes ending during the reporting period are included.

5 Profile of palliative care phases

The palliative care phase type describes the stage of the patient's illness and provides a clinical indication of the level of care a patient requires. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers. A patient may move back and forth between the stable, unstable, deteriorating and terminal phase types and these may occur in any sequence. See Appendix F for more information on the definition of palliative care phase.

The clinical assessments are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge.

Table 23 Number of phases by phase type and setting

Phase type	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N	%	N	%	N	%	N	%
Stable	679	22.9	8,383	24.9	3,830	38.6	13,627	37.3
Unstable	387	13.1	6,777	20.1	392	4.0	4,522	12.4
Deteriorating	1,227	41.4	11,264	33.5	4,821	48.6	15,490	42.4
Terminal	672	22.7	7,217	21.5	875	8.8	2,855	7.8
Total	2,965	100.0	33,641	100.0	9,918	100.0	36,494	100.0

Note: Bereavement phases have been excluded due to inconsistent data collection and bereavement practices. Bereavement phases are not included in the total phases count.

Table 24 Average phase length (in days) by phase type and setting

Phase type	Hospital / hospice		Community	
	WA Services	All services	WA Services	All services
Stable	6.1	7.0	14.1	20.4
Unstable	1.8	2.0	1.4	2.9
Deteriorating	5.0	5.2	8.1	11.9
Terminal	2.2	2.1	3.4	3.0

Note: Phase records where phase length was greater than 90 days were considered to be atypical and are excluded from the average calculations.

Table 25 presents the first phase of the episode, both for Western Australian services and nationally. The first phase of episode allows you to understand how patients are entering Western Australian services.

Table 25 First phase of episode by setting

First phase	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N	%	N	%	N	%	N	%
Stable	142	10.2	2,086	14.7	689	24.0	5,688	42.7
Unstable	248	17.8	4,848	34.2	39	1.4	791	5.9
Deteriorating	802	57.6	5,595	39.5	1,950	68.0	6,335	47.5
Terminal	201	14.4	1,629	11.5	189	6.6	509	3.8
Total	1,393	100.0	14,158	100.0	2,867	100.0	13,323	100.0

Note: This table only includes the first phase if the episode has started in the reporting period.

Table 26 presents information relating to the manner in which stable phases ended, both for Western Australian services and nationally. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 10 summarises the movement of patients out of the stable phase by setting. This movement from one phase to another is referred to as phase progression and is derived by PCOC.

Similar information is presented for the unstable (Table 27, Figure 11), deteriorating (Table 28, Figure 12) and terminal (Table 29, Figure 13) phases on the following pages.

Table 26 How stable phases end by setting

How stable phases end	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	265	39.0	4,247	50.7	2,870	74.9	9,405	69.0
Discharge / case closure	402	59.2	4,011	47.8	903	23.6	3,907	28.7
Died	12	1.8	103	1.2	57	1.5	277	2.0
Not stated / inadequately described	0	0.0	22	0.3	0	0.0	38	0.3
Total	679	100.0	8,383	100.0	3,830	100.0	13,627	100.0

Figure 10 Stable phase progression

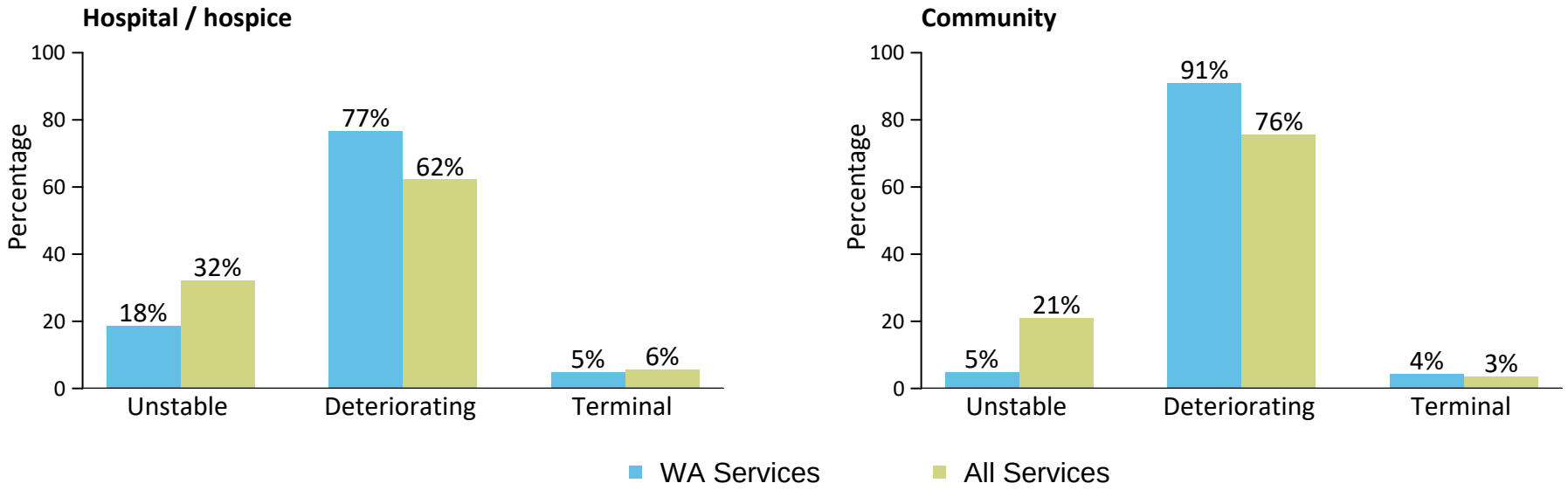


Table 27 How unstable phases end by setting

How unstable phases end	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	357	92.2	6,183	91.2	230	58.7	2,853	63.1
Discharge / case closure	15	3.9	473	7.0	156	39.8	1,595	35.3
Died	15	3.9	117	1.7	6	1.5	44	1.0
Not stated / inadequately described	0	0.0	4	0.1	0	0.0	30	0.7
Total	387	100.0	6,777	100.0	392	100.0	4,522	100.0

Figure 11 Unstable phase progression

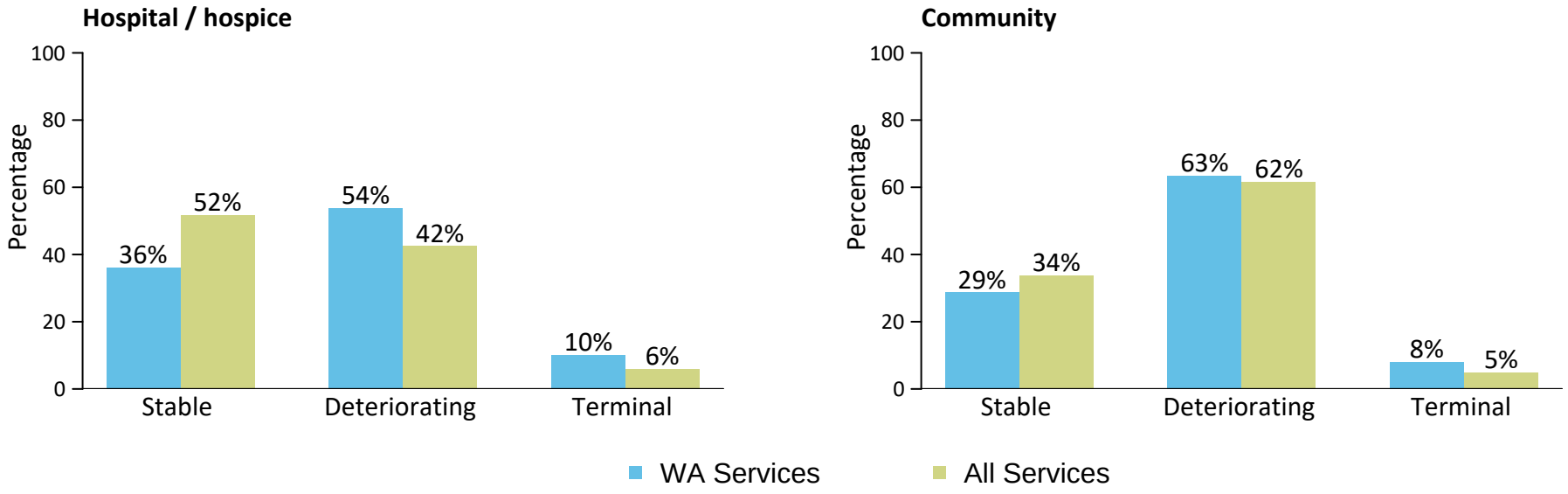


Table 28 How deteriorating phases end by setting

How deteriorating phases end	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	905	73.8	8,371	74.3	3,797	78.8	10,567	68.2
Discharge / case closure	208	17.0	1,907	16.9	771	16.0	4,022	26.0
Died	114	9.3	972	8.6	253	5.2	846	5.5
Not stated / inadequately described	0	0.0	14	0.1	0	0.0	55	0.4
Total	1,227	100.0	11,264	100.0	4,821	100.0	15,490	100.0

Figure 12 Deteriorating phase progression

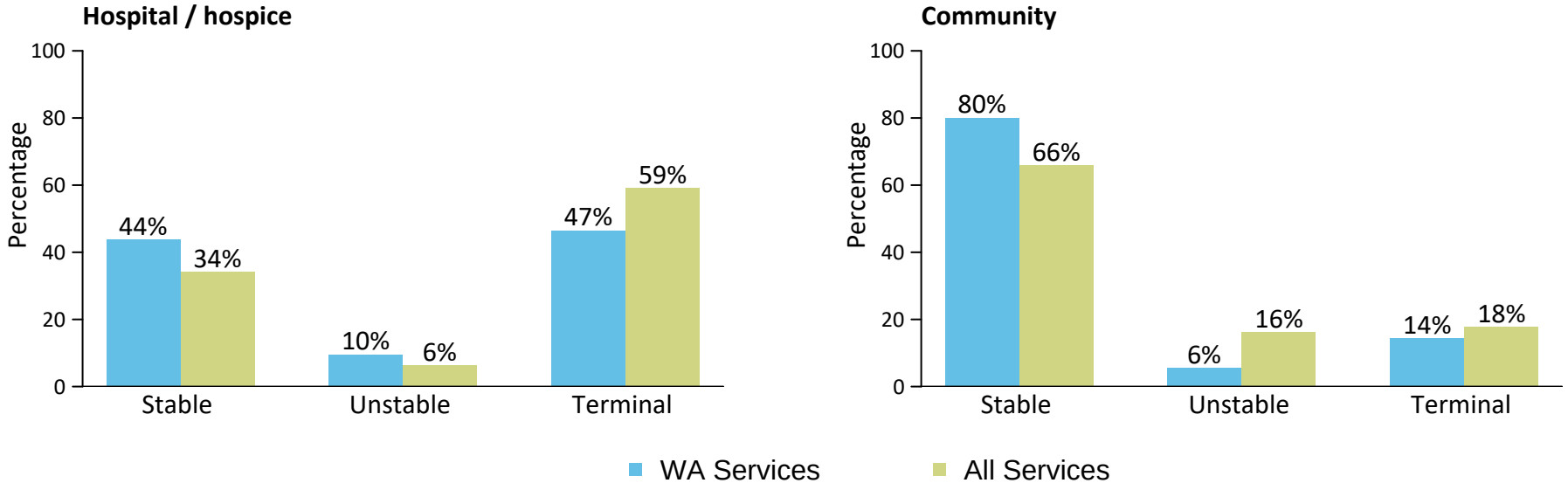
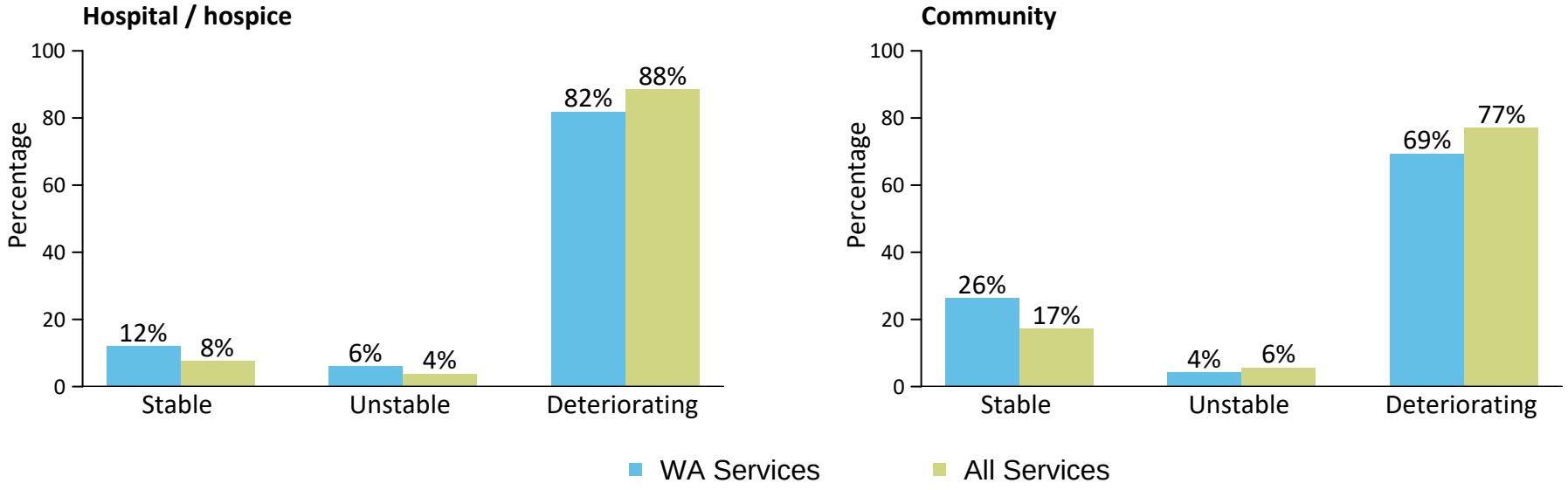


Table 29 How terminal phases end by setting

How terminal phases end	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	33	4.9	312	4.3	167	19.1	407	14.3
Discharge / case closure	32	4.8	170	2.4	65	7.4	339	11.9
Died	607	90.3	6,734	93.3	643	73.5	2,084	73.0
Not stated / inadequately described	0	0.0	1	0.0	0	0.0	25	0.9
Total	672	100.0	7,217	100.0	875	100.0	2,855	100.0

Figure 13 Terminal phase progression



6 Symptoms and problems

The Palliative Care Problem Severity Score (PCPSS) is a clinician rated screening tool to assess the overall severity of problems within four key palliative care domains (pain, other symptoms, psychological / spiritual and family / carer). The ratings are: 0 - absent, 1 - mild, 2 - moderate and 3 - severe.

Table 30 and Table 31 show the percentage scores for the hospital / hospice and community settings, respectively, for both Western Australian services and nationally. Alternative graphical representations of PCPSS profile by phase type can be found in Appendix B.

Table 30 PCPSS at beginning of phase by phase type – hospital / hospice setting

Phase type	Problem	WA Services (%)				All services (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	55.5	38.8	5.5	0.3	47.6	43.0	8.1	1.3
	Other symptoms	42.6	49.4	7.5	0.5	37.9	51.3	9.7	1.1
	Psychological / spiritual	56.0	37.6	5.9	0.4	51.1	43.1	5.3	0.6
	Family / carer	53.5	39.1	7.3	0.2	53.0	40.3	5.9	0.8
Unstable	Pain	25.1	32.6	31.1	11.1	29.5	35.9	26.3	8.4
	Other symptoms	19.5	37.0	32.5	11.0	20.5	41.9	29.6	8.1
	Psychological / spiritual	21.8	49.0	23.1	6.2	35.8	44.7	16.2	3.3
	Family / carer	28.3	42.8	23.8	5.1	36.9	43.9	15.8	3.4
Deteriorating	Pain	45.0	40.6	13.1	1.4	37.2	42.8	17.2	2.9
	Other symptoms	33.6	47.2	17.8	1.5	24.2	48.1	23.6	4.1
	Psychological / spiritual	50.5	38.7	10.3	0.5	39.9	46.5	12.2	1.4
	Family / carer	43.8	40.0	14.8	1.4	37.8	45.7	14.0	2.6
Terminal	Pain	65.9	26.8	6.9	0.4	45.9	39.3	12.3	2.6
	Other symptoms	53.1	32.1	12.8	2.0	40.1	40.1	15.9	3.9
	Psychological / spiritual	80.5	15.3	3.7	0.4	61.0	31.6	6.2	1.3
	Family / carer	36.0	44.2	17.7	2.1	32.0	46.0	17.8	4.2

Table 31 PCPSS at beginning of phase by phase type – community setting

Phase type	Problem	WA Services (%)				All services (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	52.6	45.0	2.3	0.1	47.7	47.7	4.4	0.3
	Other symptoms	22.8	70.8	6.4	0.1	25.7	65.7	8.1	0.5
	Psychological / spiritual	38.7	58.1	3.2	0.0	41.2	53.8	4.8	0.2
	Family / carer	44.1	51.0	4.9	0.1	39.1	53.9	6.7	0.3
Unstable	Pain	24.5	24.2	31.9	19.4	20.7	28.1	36.4	14.8
	Other symptoms	4.3	30.4	46.9	18.4	9.0	30.0	45.9	15.1
	Psychological / spiritual	11.0	45.4	38.3	5.4	21.1	46.6	26.3	5.9
	Family / carer	14.1	37.6	44.1	4.2	18.1	39.2	35.5	7.2
Deteriorating	Pain	34.3	43.4	21.3	1.0	32.8	47.8	18.2	1.2
	Other symptoms	8.7	53.4	37.3	0.7	12.0	56.1	30.2	1.7
	Psychological / spiritual	18.9	59.4	21.4	0.2	25.5	58.1	15.7	0.7
	Family / carer	22.5	55.6	21.6	0.4	21.7	56.6	20.2	1.5
Terminal	Pain	46.5	36.4	15.8	1.4	42.8	41.3	13.7	2.2
	Other symptoms	28.8	47.8	21.4	1.9	32.6	43.1	21.0	3.3
	Psychological / spiritual	47.9	36.5	15.0	0.7	52.1	36.1	10.6	1.2
	Family / carer	14.2	51.8	32.2	1.8	16.7	50.0	30.0	3.3

The Symptom Assessment Scale (SAS) is a patient rated (or proxy) assessment tool and reports a level of distress using a numerical rating scale from 0 - no distress to 10 - worst possible distress. The SAS reports on distress from seven symptoms, these being difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. It provides a clinical picture of these seven symptoms from the patient's perspective. The SAS scores are grouped in Table 32 and Table 33 on the following pages using the same categories as the PCPSS i.e. absent (0), mild (1-3), moderate (4-7) and severe (8-10). Alternative graphical representations of the SAS profile by phase type can be found in Appendix B.

Table 32 Symptom distress at the beginning of a phase by phase type – hospital / hospice setting

Phase type	Symptom	WA Services (%)				All services (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Difficulty sleeping	77.2	13.8	7.4	1.6	79.1	14.6	5.5	0.8
	Appetite problems	77.4	15.7	6.4	0.6	73.7	18.9	6.5	0.9
	Nausea	85.7	10.0	3.7	0.6	84.6	11.3	3.5	0.6
	Bowel problems	75.3	18.9	4.4	1.3	72.5	20.1	6.4	1.1
	Breathing problems	70.6	19.3	8.8	1.2	70.7	19.4	8.4	1.5
	Fatigue	51.0	31.6	15.6	1.8	44.6	35.2	18.1	2.1
	Pain	56.3	30.8	12.1	0.7	49.2	35.7	13.5	1.7
Unstable	Difficulty sleeping	53.5	21.0	17.9	7.5	64.4	20.1	12.4	3.2
	Appetite problems	56.0	23.7	16.1	4.2	56.9	24.4	15.2	3.6
	Nausea	66.3	15.3	15.0	3.4	70.5	16.3	10.0	3.2
	Bowel problems	59.3	22.0	15.5	3.1	59.7	22.5	13.9	3.9
	Breathing problems	54.4	22.3	15.8	7.5	58.0	21.5	14.9	5.6
	Fatigue	30.1	24.4	34.3	11.2	32.1	30.8	29.7	7.3
	Pain	24.4	19.7	41.5	14.5	30.5	29.9	28.9	10.7
Deteriorating	Difficulty sleeping	71.2	17.4	9.7	1.7	75.4	15.2	8.0	1.4
	Appetite problems	68.1	21.4	9.5	1.1	66.4	21.8	10.2	1.7
	Nausea	80.2	14.2	5.0	0.7	78.9	13.8	6.0	1.3
	Bowel problems	69.0	19.3	9.7	2.0	68.0	20.7	9.5	1.8
	Breathing problems	61.2	21.2	15.7	1.9	61.7	21.4	13.7	3.3
	Fatigue	42.8	27.2	27.0	3.0	38.8	29.4	26.4	5.4
	Pain	42.5	33.5	21.4	2.6	39.3	36.0	21.3	3.4
Terminal	Difficulty sleeping	94.6	3.9	1.3	0.1	92.2	5.4	2.0	0.4
	Appetite problems	97.8	1.8	0.4	0.0	92.4	5.6	1.4	0.6
	Nausea	96.6	2.7	0.7	0.0	93.4	4.4	1.9	0.3
	Bowel problems	94.2	3.6	1.5	0.7	89.2	7.3	2.9	0.6
	Breathing problems	79.0	13.3	6.1	1.5	71.7	16.8	8.7	2.8
	Fatigue	90.1	4.8	3.6	1.5	78.1	11.2	8.3	2.4
	Pain	68.4	22.9	8.1	0.6	55.3	29.9	12.9	1.8

Table 33 Symptom distress at the beginning of a phase by phase type – community setting

Phase type	Symptom	WA Services (%)				All services (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Difficulty sleeping	82.7	14.6	2.7	0.1	73.5	21.0	5.0	0.5
	Appetite problems	73.3	23.2	3.5	0.0	63.1	30.5	5.9	0.6
	Nausea	91.8	7.6	0.6	0.0	84.0	13.8	2.0	0.1
	Bowel problems	81.0	16.7	2.4	0.0	73.1	22.1	4.4	0.4
	Breathing problems	66.0	26.3	7.4	0.2	59.9	31.3	8.0	0.8
	Fatigue	31.6	39.6	28.3	0.4	27.4	47.5	23.3	1.9
	Pain	57.4	36.9	5.4	0.2	47.4	44.2	7.7	0.7
Unstable	Difficulty sleeping	65.1	19.0	14.6	1.3	52.0	24.5	19.4	4.1
	Appetite problems	60.5	18.2	19.5	1.8	47.4	29.9	19.2	3.5
	Nausea	69.1	11.9	16.5	2.6	62.6	16.7	16.2	4.5
	Bowel problems	72.5	16.1	9.9	1.6	58.0	23.6	14.6	3.8
	Breathing problems	54.5	20.8	19.0	5.7	48.7	26.0	19.2	6.0
	Fatigue	23.8	20.9	47.3	8.0	20.0	29.4	41.2	9.4
	Pain	27.6	17.8	33.0	21.6	20.5	27.7	36.0	15.8
Deteriorating	Difficulty sleeping	73.0	19.0	7.6	0.4	66.0	24.9	8.1	1.0
	Appetite problems	60.3	28.6	10.8	0.4	52.6	35.3	11.0	1.2
	Nausea	82.3	12.4	5.1	0.1	76.4	17.8	5.2	0.6
	Bowel problems	69.7	22.2	7.8	0.3	65.6	25.3	8.1	0.9
	Breathing problems	57.5	26.2	15.5	0.8	53.2	31.3	14.2	1.3
	Fatigue	23.2	31.7	43.6	1.5	21.0	39.9	35.5	3.6
	Pain	38.7	36.2	23.4	1.7	34.0	44.4	19.5	2.2
Terminal	Difficulty sleeping	80.3	10.8	8.1	0.8	81.6	11.4	6.1	1.0
	Appetite problems	93.1	3.0	3.3	0.6	88.1	7.0	3.9	1.0
	Nausea	92.7	4.9	2.2	0.2	87.8	8.4	3.3	0.4
	Bowel problems	84.2	11.9	3.7	0.2	81.3	13.8	4.4	0.5
	Breathing problems	70.2	16.2	11.9	1.7	67.5	20.0	10.4	2.0
	Fatigue	80.4	4.9	11.7	3.0	73.3	12.5	10.2	4.0
	Pain	55.1	25.0	18.6	1.4	46.8	33.1	18.4	1.8

7 Functional status and level of dependence

The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 0 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. Table 34 shows the data for the AKPS at phase start.

Table 34 Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting

AKPS assessment at phase start	Hospital / hospice				Community			
	WA Services		All services		WA Services		All services	
	N	%	N	%	N	%	N	%
Comatose or barely rousable (10)	410	13.8	3,463	10.3	347	3.5	1,089	3.0
Totally bedfast and requiring extensive nursing care (20)	659	22.2	8,221	24.4	1,183	11.9	3,725	10.2
Almost completely bedfast (30)	426	14.4	5,172	15.4	761	7.7	3,073	8.4
In bed more than 50% of the time (40)	494	16.7	6,839	20.3	1,215	12.3	5,503	15.1
Requires considerable assistance (50)	494	16.7	5,089	15.1	2,102	21.2	8,416	23.1
Requires occasional assistance (60)	373	12.6	3,192	9.5	2,439	24.6	8,039	22.0
Cares for self (70)	73	2.5	690	2.1	1,565	15.8	3,939	10.8
Normal activity with effort (80)	26	0.9	220	0.7	263	2.7	768	2.1
Able to carry on normal activity; minor signs or symptoms (90)	4	0.1	55	0.2	31	0.3	137	0.4
Normal; no complaints; no evidence of disease (100)	0	0.0	7	0.0	0	0.0	5	0.0
Not stated/inadequately described	6	0.2	693	2.1	12	0.1	1,800	4.9
Total	2,965	100.0	33,641	100.0	9,918	100.0	36,494	100.0

Figure 14 Distribution of AKPS at episode start

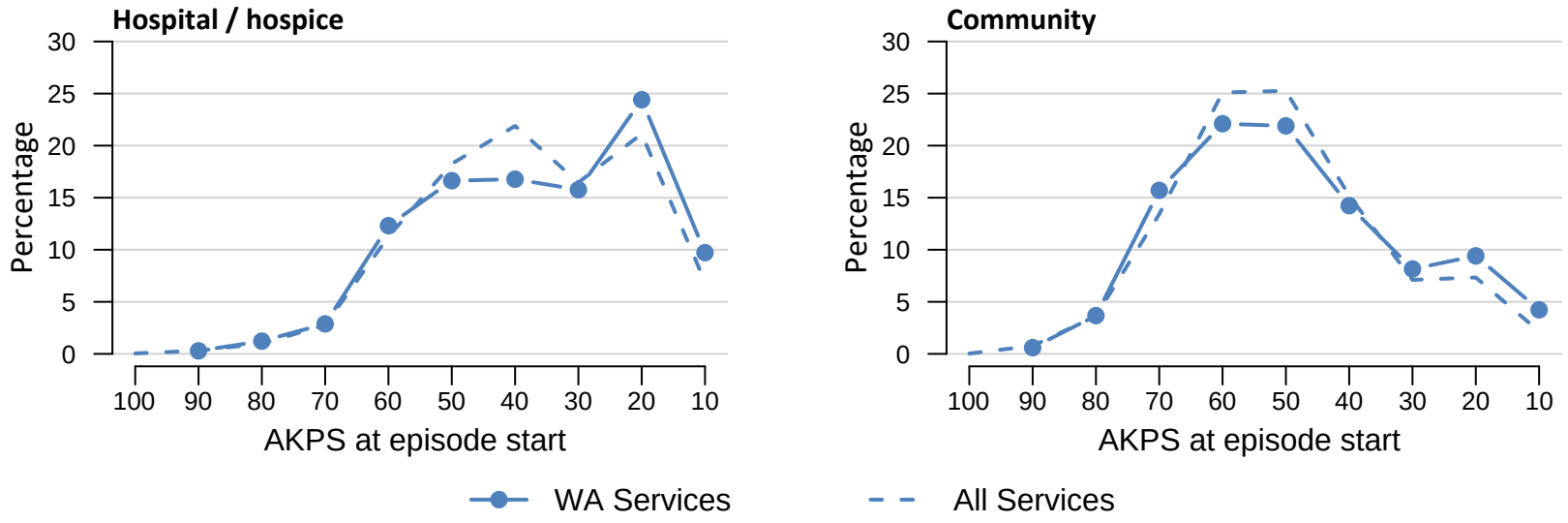


Figure 15 Distribution of AKPS at phase start by phase type

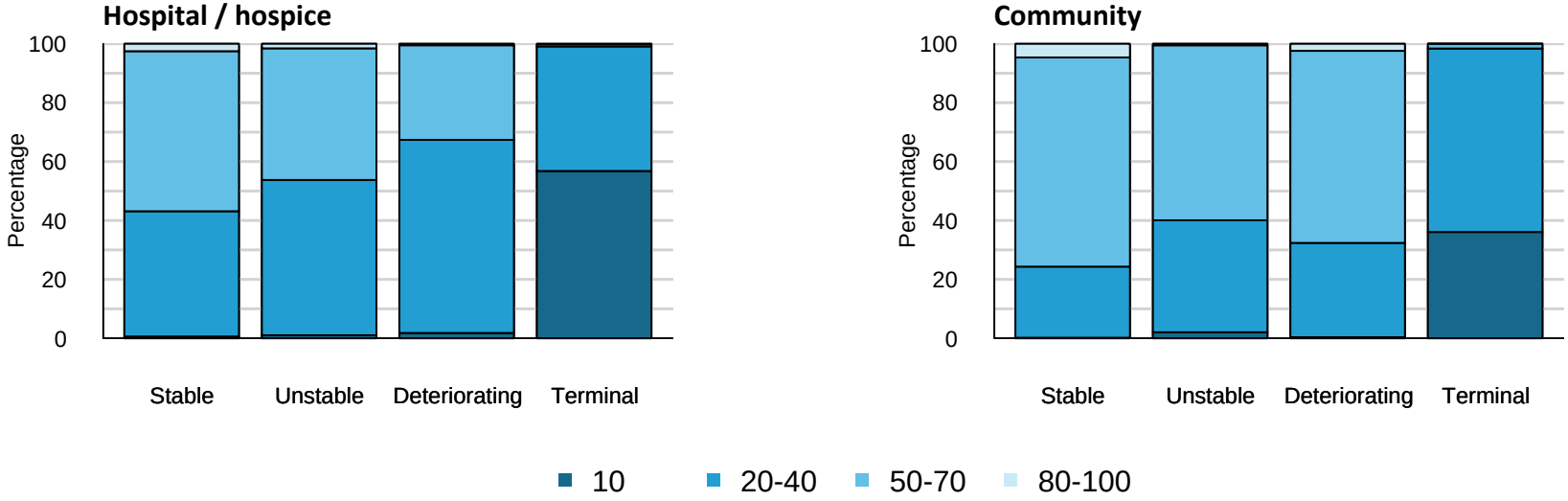
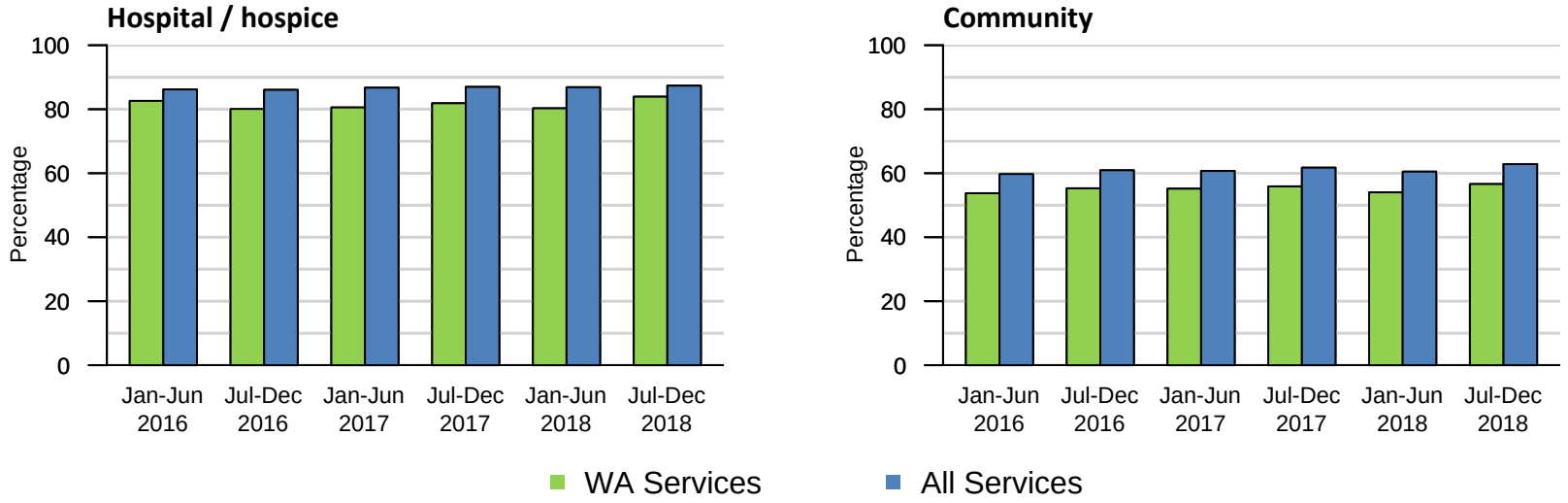


Figure 16 **Percentage of phases beginning with an AKPS of 50 or less overtime**



The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) tool consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence. The RUG-ADL items are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge. Table 36 summaries the RUG-ADL items at the beginning of each phase for hospital / hospice and community patients.

Table 35 The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) at phase start by setting

Item	RUG-ADL assessment at phase start	Hospital / hospice				Community			
		WA Services		All services		WA Services		All services	
		N	%	N	%	N	%	N	%
Bed mobility	Independent or supervision only (1)	1,032	34.9	9,380	28.0	6,390	64.6	20,941	61.7
	Limited physical assistance (3)	389	13.1	5,920	17.6	913	9.2	4,498	13.3
	Other than two person physical assist (4)	276	9.3	3,848	11.5	523	5.3	2,670	7.9
	Two or more person physical assist (5)	1,264	42.7	14,396	42.9	2,058	20.8	5,814	17.1
Toileting	Independent or supervision only (1)	684	23.1	6,162	18.4	4,837	48.9	17,630	52.0
	Limited physical assistance (3)	584	19.7	6,955	20.7	2,068	20.9	6,587	19.4
	Other than two person physical assist (4)	370	12.5	4,983	14.9	785	7.9	3,509	10.3
	Two or more person physical assist (5)	1,323	44.7	15,438	46.0	2,194	22.2	6,182	18.2
Transfers	Independent or supervision only (1)	672	22.7	6,169	18.4	4,830	48.9	17,494	51.7
	Limited physical assistance (3)	582	19.7	6,762	20.2	2,075	21.0	6,690	19.8
	Other than two person physical assist (4)	362	12.2	4,642	13.8	733	7.4	3,383	10.0
	Two or more person physical assist (5)	1,343	45.4	15,960	47.6	2,245	22.7	6,300	18.6
Eating	Independent or supervision only (1)	1,430	48.4	13,669	40.9	6,111	62.1	22,709	67.5
	Limited physical assistance (2)	429	14.5	7,325	21.9	1,852	18.8	5,397	16.0
	Extensive assistance/total dependence/tube fed (3)	1,093	37.0	12,444	37.2	1,882	19.1	5,547	16.5

Figure 17 Distribution of Total RUG-ADL at episode start

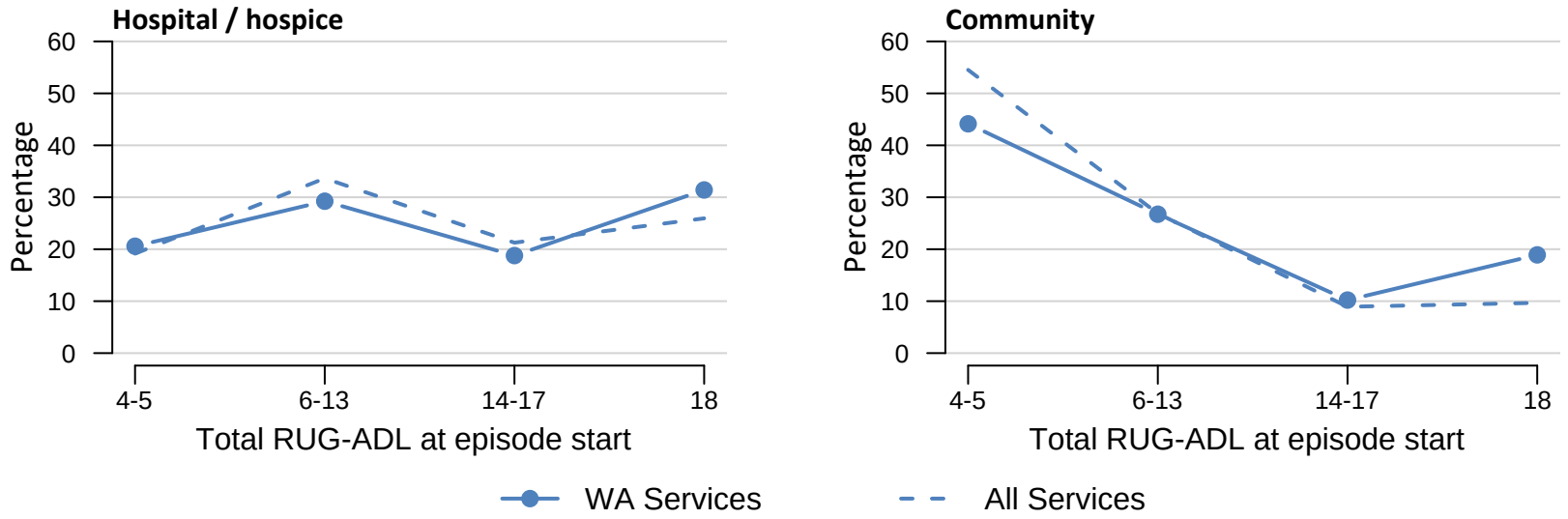


Figure 18 Distribution of Total RUG-ADL at phase start by phase type

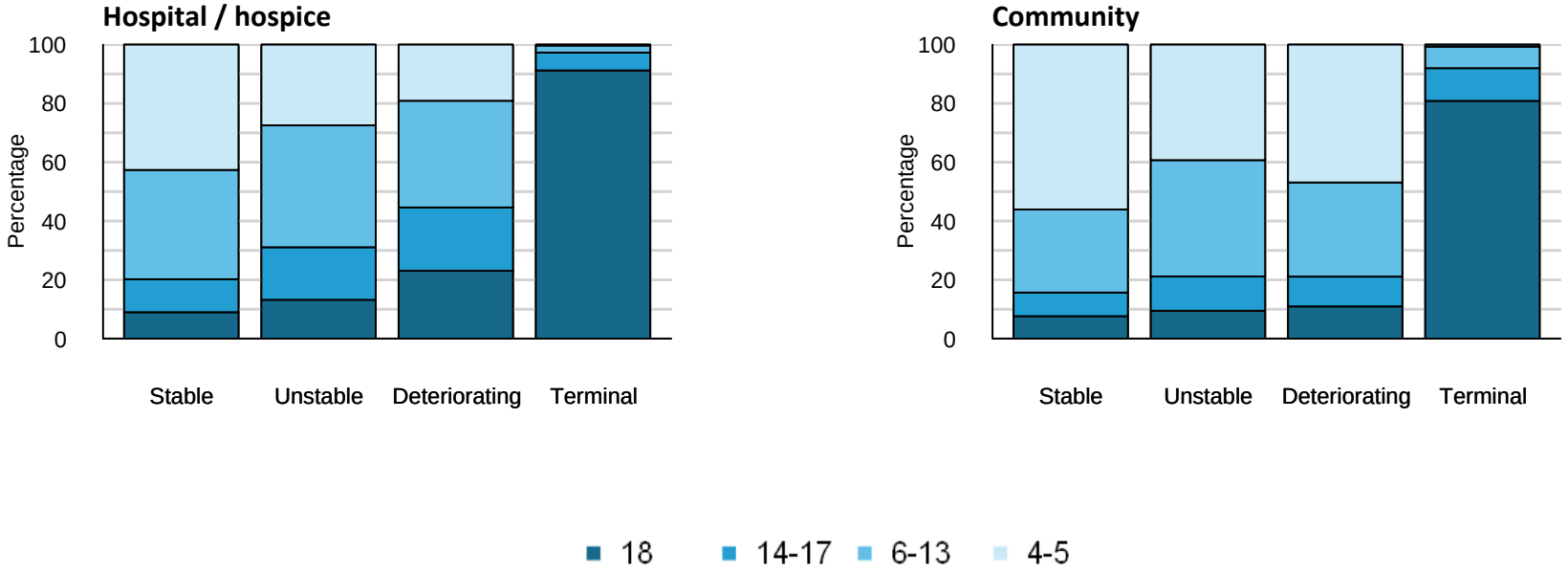
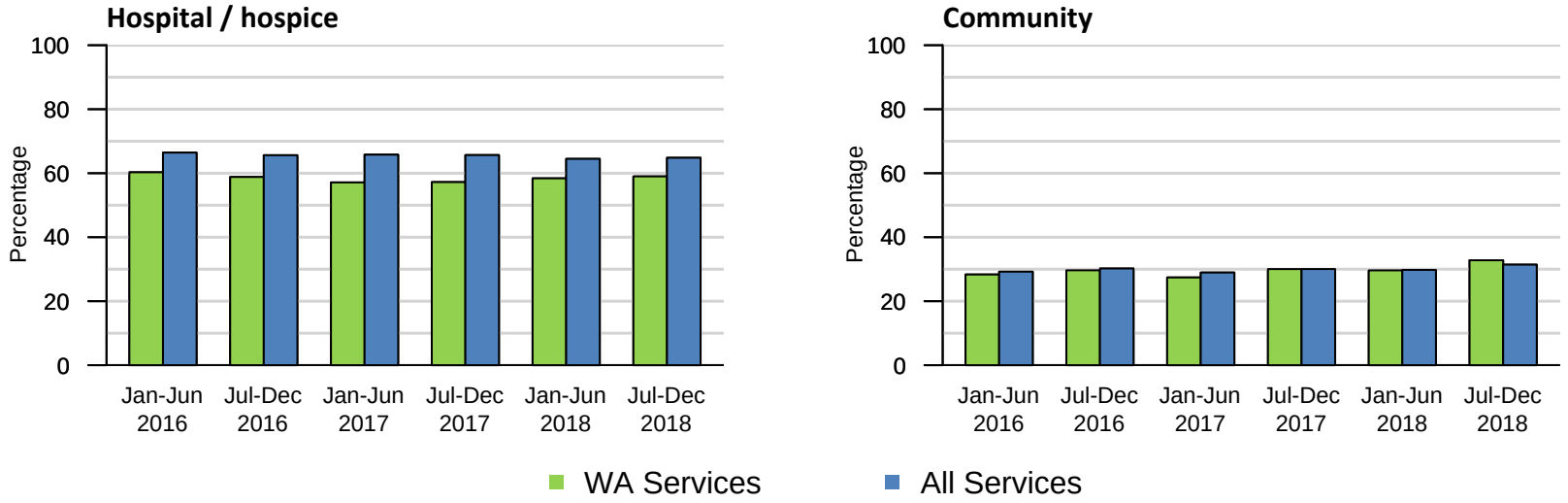


Figure 19 **Percentage of phases beginning with a Total RUG-ADL of 10 or more overtime**



Appendices

A Summary of data included in this report

During the reporting period, data were provided for a total of 23,333 patients who between them had 29,931 episodes of care and 70,135 palliative care phases. These total numbers are determined by a data scoping method. This method looks at the phase level data first and includes all phases that ended within the current reporting period. The associated episodes and patients are then determined (Appendix C contains a more detailed explanation of this process). Table 36 shows the number of patients, episodes and phases included in this report – both for Western Australian services and nationally.

Table 36 Summary of patients, episodes and phases by setting

	Hospital / hospice		Community		Total	
	WA Services	All services	WA Services	All services	WA Services	All services
Patients (N)	1,220	12,437	2,610	12,097	3,813	23,333
Episodes (N)	1,427	14,679	3,312	15,252	4,739	29,931
Phases (N)	2,965	33,641	9,918	36,494	12,883	70,135
Patients (%)	32.0	53.3	68.5	51.8	100	100
Episodes (%)	30.1	49.0	69.9	51.0	100	100
Phases (%)	23.0	48.0	77.0	52.0	100	100
Average number of phases per episode* **	2.0	2.3	2.7	2.3	2.5	2.3

* Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.

** Bereavement phases are excluded from this count.

*** Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

Table 37 shows the number of completed episodes and phases by setting for each month in the current reporting period for Western Australian services.

Table 37 Number of completed episodes and phases by month and setting

Setting		Jul	Aug	Sep	Oct	Nov	Dec
Hospital / hospice	Completed episodes (N)	219	276	221	258	227	204
	Completed phases (N)	524	571	411	549	491	419
Community	Completed episodes (N)	501	484	460	474	459	476
	Completed phases (N)	1,625	1,745	1,565	1,679	1,641	1,663

Table 38 shows the number of patients, episodes and phases for Western Australian services over time and is reported by setting of care.

Table 38 Number of patients, episodes and phases by setting and reporting period

	Hospital / hospice						Community					
	Jan-Jun 2016	Jul-Dec 2016	Jan-Jun 2017	Jul-Dec 2017	Jan-Jun 2018	Jul-Dec 2018	Jan-Jun 2016	Jul-Dec 2016	Jan-Jun 2017	Jul-Dec 2017	Jan-Jun 2018	Jul-Dec 2018
Patients[1]	973	1,087	1,071	1,146	1,174	1,220	2,229	2,301	2,261	2,376	2,432	2,610
Episodes	1,149	1,260	1,232	1,353	1,366	1,427	2,969	2,952	2,914	3,053	3,133	3,312
Phases[2]	2,581	3,015	2,908	3,008	2,913	2,965	10,135	10,280	9,972	10,259	10,110	9,918
Phases per episode[3]	2.2	2.4	2.3	2.2	2.1	2.0	3.2	3.2	3.2	3.1	2.9	2.7

[1] Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.

[2] Bereavement phases are excluded from this count.

[3] Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

B Data item completion

As shown in Table 39, Table 40 and Table 41 below, the rate of data completion is very high. In reviewing these tables, it is important to note that in some cases some data items are not required to be completed. For example, place of death is only required for patients who have died. Hence the complete column in the following tables only refers to the percentage of complete records where the data item was relevant.

PCOC strongly encourages services to complete and submit the whole data set on every patient as non-completion may result in services being excluded from relevant benchmarking activities or erroneous conclusions being drawn. Low completion of data items may also distort percentages and graphs in some sections.

Table 39 Item completion (%) - patient level

Data item	WA Services	All services
Date of birth	100.0	100.0
Sex	100.0	100.0
Indigenous status	96.9	96.5
Country of birth	97.4	96.9
Preferred language	99.8	98.6
Diagnosis	99.9	99.3

Table 40 Item completion (%) - episode level, by setting

Data item	Hospital / hospice		Community		Total	
	WA Services	All services	WA Services	All services	WA Services	All services
Date of first contact	100.0	99.5	100.0	99.9	100.0	99.7
Referral date	100.0	99.7	100.0	99.9	100.0	99.8
Referral source	100.0	99.1	100.0	99.6	100.0	99.3
Date ready for care	100.0	97.8	100.0	96.2	100.0	97.0
Mode of episode start	99.9	99.5	100.0	99.4	100.0	99.4
Accommodation at episode start	100.0	99.5	100.0	97.9	100.0	98.5
Episode end date[1]	99.7	99.6	87.4	90.6	91.1	95.0
Mode of episode end	100.0	99.8	100.0	99.7	100.0	99.8
Accommodation at episode end	100.0	98.6	100.0	98.2	100.0	98.5
Place of death	-	-	100.0	98.8	100.0	98.8

[1] Episode end date item completion may be affected by open episodes.

Table 41 Item completion (%) - phase level, by setting

Data item	Sub-Category (where applicable)	At phase start						At discharge					
		Hospital / hospice		Community		Total		Hospital / hospice		Community		Total	
		WA Services	All services	WA Services	All services	WA Services	All services	WA Services	All services	WA Services	All services	WA Services	All services
RUG-ADL	Bed mobility	99.9	99.7	99.7	93.0	99.7	96.2	98.6	81.5	59.5	50.4	69.6	62.8
	Toileting	99.9	99.7	99.7	92.9	99.7	96.2	98.8	81.6	59.5	50.3	69.6	62.8
	Transfers	99.8	99.7	99.6	92.8	99.7	96.1	98.8	81.6	59.5	50.3	69.6	62.8
	Eating	99.6	99.4	99.3	92.2	99.3	95.7	98.5	81.5	59.4	49.7	69.5	62.4
PCPSS	Pain	99.7	99.2	99.9	94.2	99.9	96.6	98.6	81.1	59.6	50.6	69.6	62.8
	Other symptom	78.6	97.2	99.9	92.0	95.0	94.5	88.7	80.0	59.6	49.7	67.1	61.8
	Psychological / spiritual	99.4	99.1	99.9	93.4	99.8	96.1	98.6	81.1	60.2	50.1	70.1	62.5
	Family / carer	85.5	96.5	93.4	89.6	91.6	92.9	74.4	77.8	48.4	47.2	55.1	59.4
SAS	Difficulty sleeping	99.2	90.3	99.6	90.4	99.5	90.3	98.2	71.9	59.4	48.0	69.4	57.5
	Appetite problems	99.3	90.3	99.5	91.3	99.5	90.8	98.3	71.8	59.5	48.7	69.5	57.9
	Nausea	99.6	90.3	99.7	92.5	99.7	91.5	98.5	71.5	59.5	49.7	69.6	58.4
	Bowel problems	99.5	90.2	99.6	91.6	99.6	90.9	98.6	71.9	59.4	48.7	69.5	57.9
	Breathing problems	99.6	90.4	99.8	92.0	99.7	91.2	98.6	71.9	59.6	49.5	69.6	58.5
	Fatigue	99.5	90.3	99.7	92.9	99.7	91.7	98.3	72.3	59.5	50.0	69.5	58.9
	Pain	99.6	90.5	99.8	95.4	99.8	93.0	98.6	72.4	59.6	51.9	69.7	60.1
AKPS	-	99.8	97.9	99.9	95.1	99.9	96.4	98.8	80.2	59.8	52.5	69.8	63.6

Data item	Hospital / hospice		Community		Total	
	WA Services	All services	WA Services	All services	WA Services	All services
Phase End Reason	100.0	99.8	100.0	99.5	100.0	99.6

C Profile of symptoms and problems

Figure 20 Profile of symptoms and problems by phase type for WA Services – hospital / hospice setting

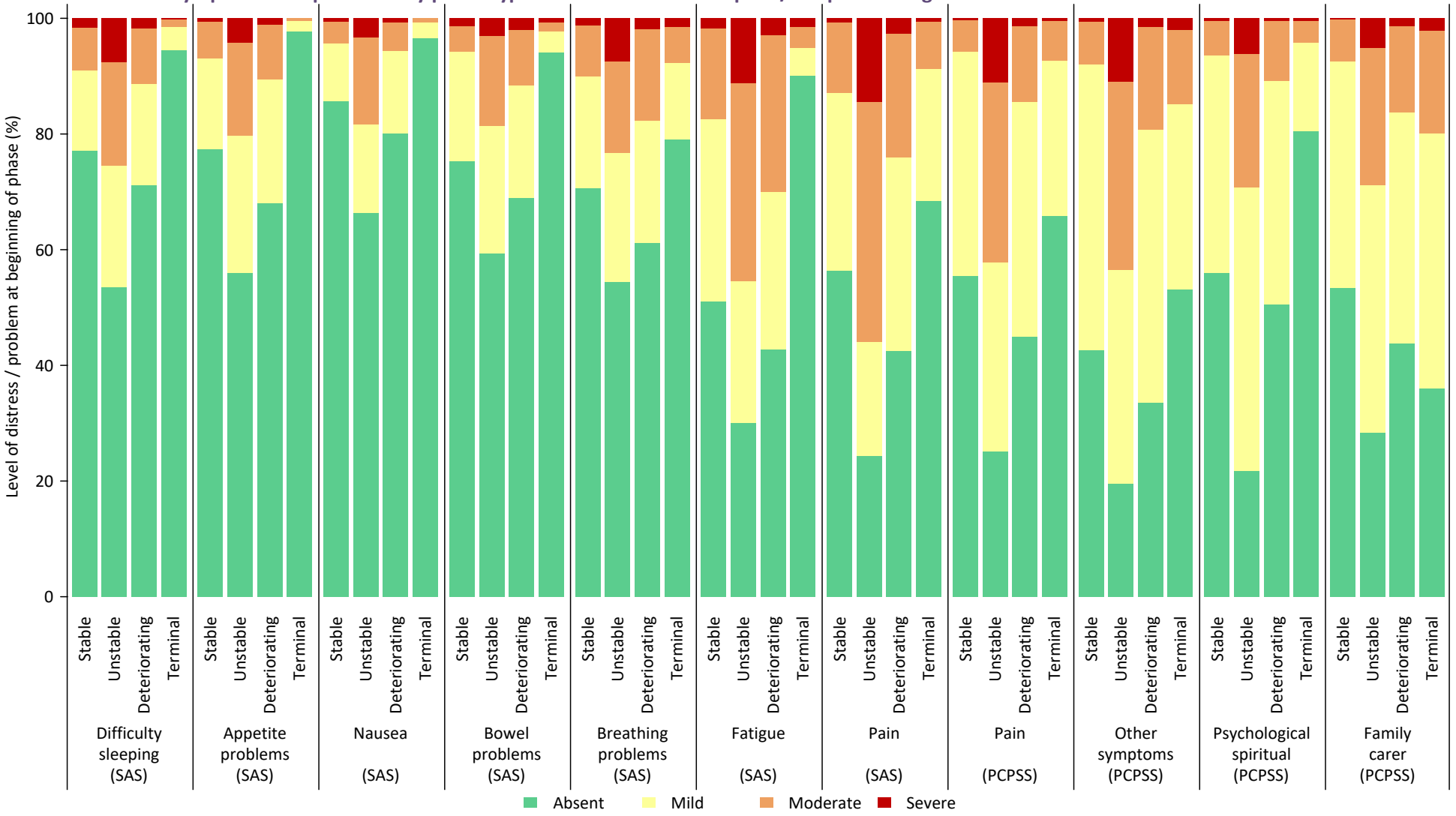
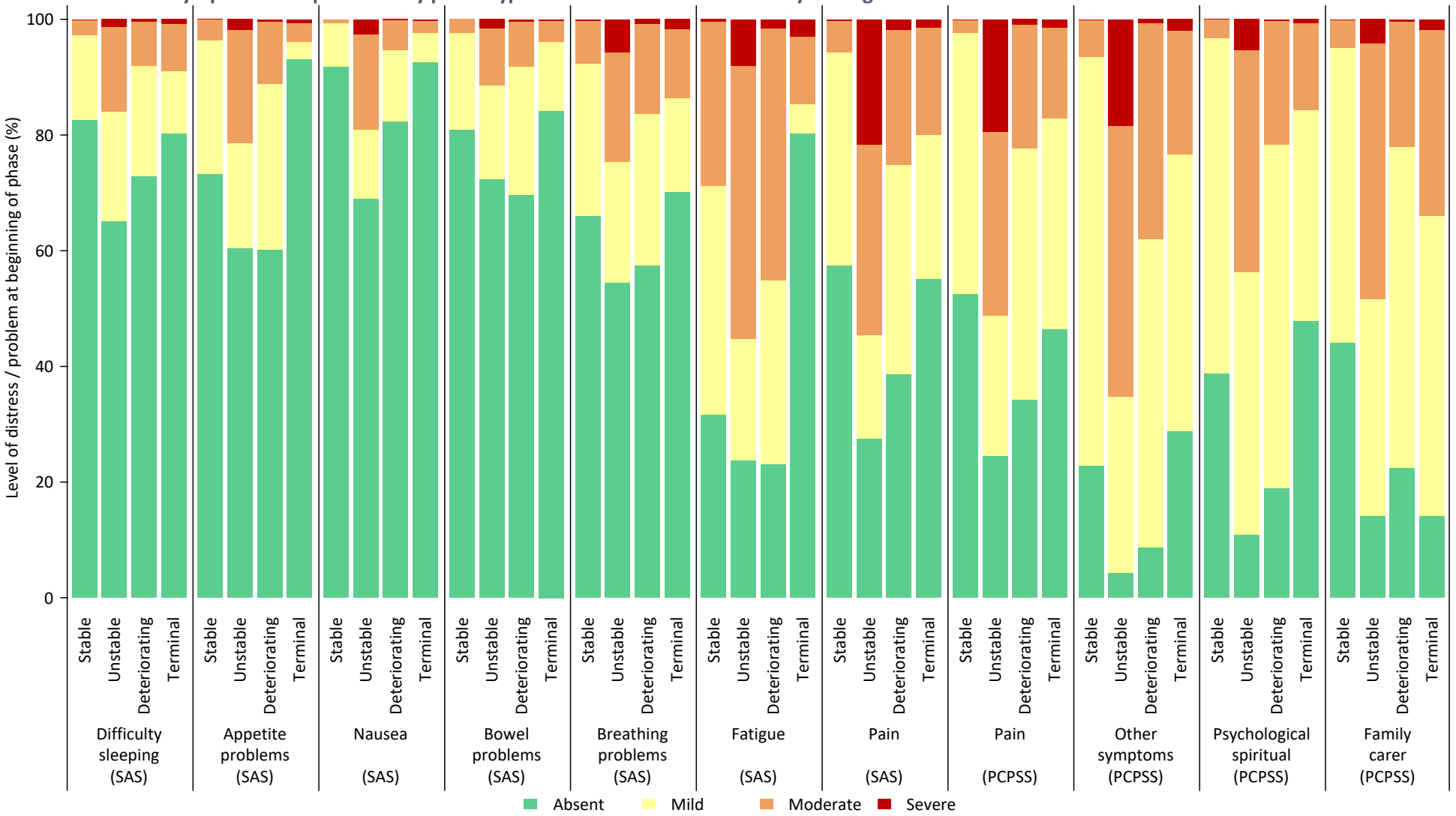


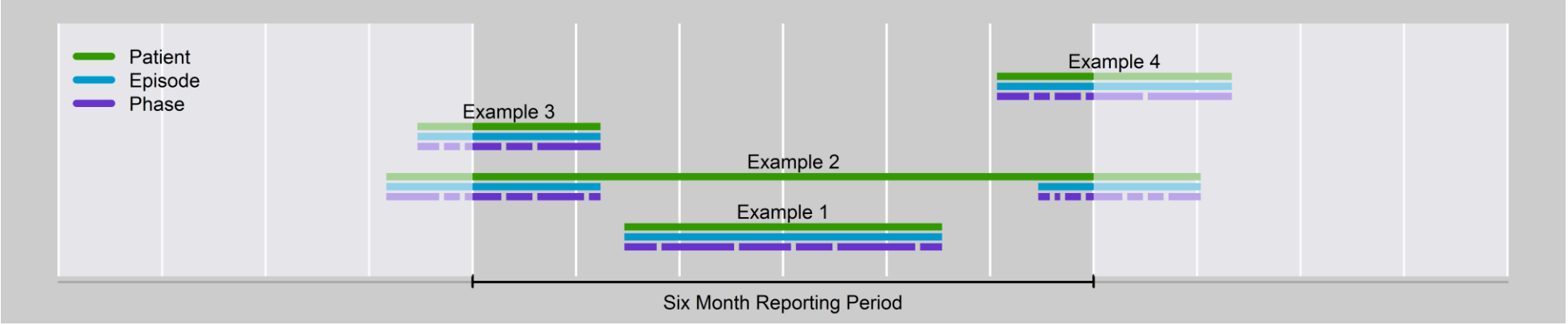
Figure 21 **Profile of symptoms and problems by phase type for WA Services – community setting**



D Data scoping method

The method used to determine which data is included in a PCOC report looks at the phase level records first. All phase records that end within the 6 month reporting period are deemed to be "in scope" and would be included in the report. The episode and patient records associated with these phases are also deemed to be "in scope" and hence would also be included in the report. Figure 22 below displays four examples to help visualize this process.

Figure 22 Diagram of the PCOC data scoping method



In Example 1, the patient (represented by the green line) has one episode (represented by the blue line). This episode has six phases (represented by the purple line segments). All six phases would be included in the report as they all end within the reporting period. Hence, the episode and patient would also be in the report.

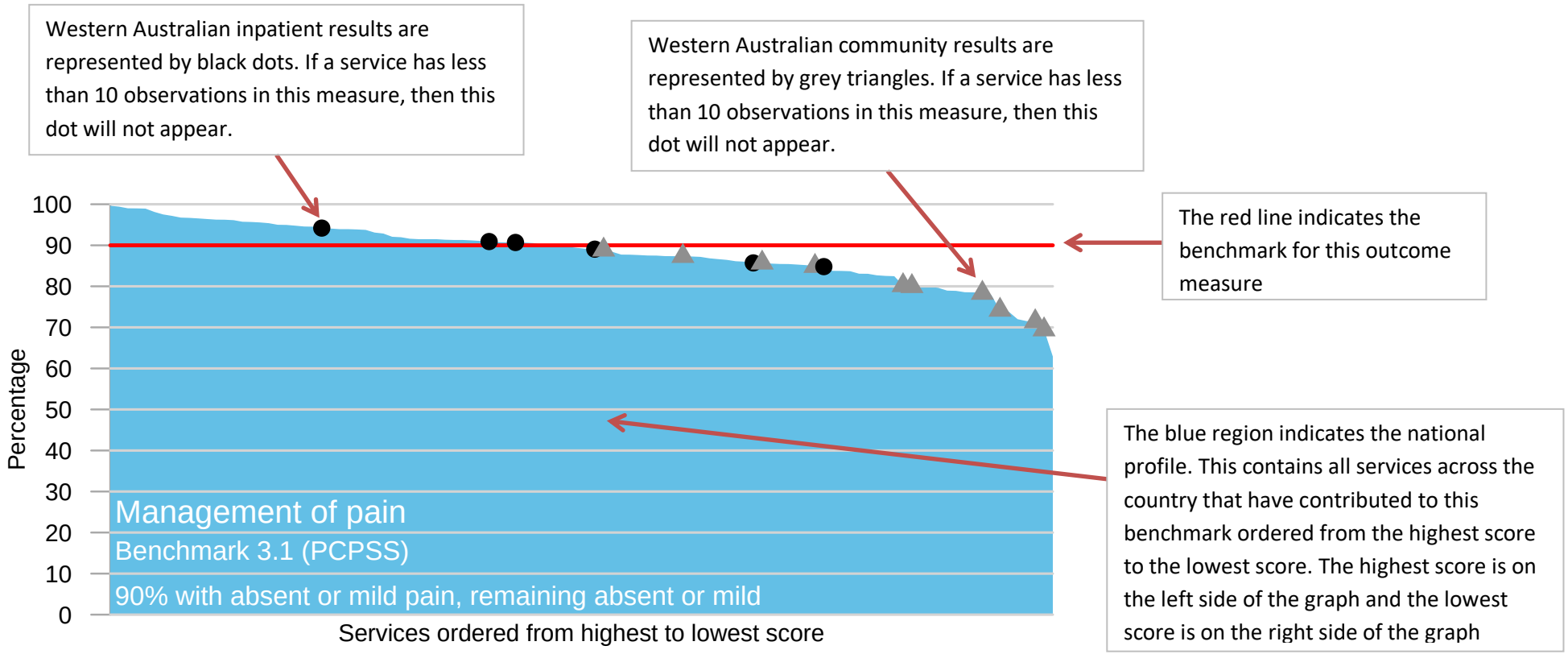
In Example 2, the patient has two episodes - the first having six phases and the second having seven phases. Looking at the phases associated with the first episode, the last four will be included in the report (as they end within the reporting period). The first two phases would have been included in the previous report. For the phases relating to the second episode, only the first three end within the reporting period, so only these would be included in the report. The following four phases would be included in the next report. Both of the episode records and the patient record would also be included in the report.

In Example 3, the patient has one episode and five phases. Only the last three phases will be included in the report as they are the only ones ending within the reporting period (the first two phases would have been included in the previous report). The episode and patient records would be included in the report.

In Example 4, the patient again has one episode and five phases. This time, only the first three phases will be included in the report (the last two phases will be included in the next report). Again, the episode and patient records would be included in the report.

E Interpreting benchmark profile graphs

The national profile graphs present Western Australian services in comparison to all other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure. Western Australian hospital / hospice services are highlighted as a black dots on the graph. Western Australian community services are highlighted as grey triangles on the graph.



F Palliative Care Phase definitions

Phase type	Start	End
Stable	▪ Patient problems and symptoms are adequately controlled by established plan of care **and** ▪ Further interventions to maintain symptom control and quality of life have been planned **and** ▪ Family / carer situation is relatively stable and no new issues are apparent.	▪ The needs of the patient and / or family / carer increase, requiring changes to the existing plan of care.
Unstable	An urgent change in the plan of care or emergency treatment is required **because** ▪ Patient experiences a new problem that was not anticipated in the existing plan of care, **and / or** ▪ Patient experiences a rapid increase in the severity of a current problem; **and / or** ▪ Family / carers circumstances change suddenly impacting on patient care.	▪ The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom / crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) **and / or** ▪ Death is likely within days (i.e. patient is now terminal).
Deteriorating	The care plan is addressing anticipated needs but requires periodic review **because** ▪ Patients overall functional status is declining **and / or** ▪ Patient experiences a gradual worsening of existing problem **and / or** ▪ Patient experiences a new but anticipated problem **and / or** ▪ Family / carers experience gradual worsening distress that impacts on the patient care.	▪ Patient condition plateaus (i.e. patient is now stable) **or** ▪ An urgent change in the care plan or emergency treatment **and / or** ▪ Family / carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) **or** ▪ Death is likely within days (i.e. patient is now terminal).
Terminal	Death is likely within days.	▪ Patient dies **or** ▪ Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).

Acknowledgements

Contributions PCOC wishes to acknowledge the valuable contribution made by the many staff from palliative care services who have spent considerable time collecting, collating and correcting the data and without whose effort this report would not be possible.

Disclaimer PCOC has made every effort to ensure that the data used in this report are accurate. Data submitted to PCOC are checked for anomalies and services are asked to re-submit data prior to the production of the PCOC report. We would advise readers to use their professional judgement in considering all information contained in this report.

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